

Centers for Medicare & Medicaid Services
Listening Session on Dementia Care and Services
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Webinar recording:

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QUESTIONS:

- (1) What areas of whole-person care for people living with Alzheimer’s Disease and Related Dementias (ADRD) and their caregivers are in most need of transformation?
- (2) How would you prioritize the following “domains of care” in terms of improving health outcomes: care coordination, caregiver support/education, and home and community-based services?
- (3) What are examples of promising practices to effectively address health equity gaps and cultural differences in care for people living with ADRD and their caregivers?
- (4) Where do people with ADRD and their caregivers go for information and resources about clinicians, and services and supports?
- (5) What would make it appealing to people living with ADRD and providers to participate in a specialized model of care?

Meghan O'Toole: Good afternoon, my name is Meghan O’Toole, and I’m a Senior Advisor in the Office of the Administrator at CMS. I would like to welcome our nine guest panelists and all the dementia care stakeholders who are listening to today’s CMS Administrator Listening Session on Dementia Care and Services. Our nine guest panelists will be offering their insights during today's session on the five questions on the screen (see above). This call is being recorded. If members of the press are attending, please note all press or media questions should be submitted using our media inquiries form, which may be found at cms.gov/newsroom/media-inquiries. Following today’s session, you can submit any comments you may have to the CMS Innovation Center mailbox at CMMIstrategy@cms.hhs.gov. I will repeat that mailbox at the end. Now I am going to introduce our CMS leadership on the line before turning it over to CMS Administrator Chiquita Brooks-LaSure for her opening remarks. Then, we’ll hear from our nine guest panelists. The CMS leadership with us today includes Jon Blum, Principal Deputy Administrator and Chief Operating Officer, Dr. Liz Fowler, Deputy Administrator and Director of the Center for Medicare and Medicaid Innovation, Dr. Shari Ling, Deputy Chief Medical Officer at the Center for Clinical Standards and Quality, Dr. Aditi Mallick, Chief Medical Officer of the Center for Medicaid and CHIP Services, Dr. Douglas Jacobs, Chief Transformation Officer of the Center for Medicare, Tim Engelhardt, Director of the Federally Coordinated Health Care Office, Stefanie Costello, Director of the Partner Relations Group in the Office of Communications, and Senior Advisors in the Office of the Administrator: Hannah Katch, Will Harris and Kyla Ellis. And with that, I’ll turn it over to our

Administrator Chiquita Brooks-LaSure. Administrator?

CMS Administrator Chiquita Brooks-LaSure: I want to say to all of you who joined us, thank you so much. One of the things we have been doing a lot within the Administration is really gathering these listening sessions where we have a cross-section of the CMS leadership team, and it has been incredibly helpful for us as a team to hear from stakeholders at the same time to make sure we are hearing the same thing and integrating them across the agency. I want to say even though we may be relatively quiet during the listening session, it is because we really want to spend most of our time hearing from all of you with a lived experience on the ground. I like to say that the work we do is so personal because health care is personal. I can't think of an issue within health care that is more personal than the devastating impacts of Alzheimer's and dementia. I'm sure I speak for many of us, where we have loved ones who we're watching go through this, who are experiencing it and I want to thank all of you on the front lines for caring for and thinking about how to address such a devastating illness that affects not only the people that have it, but families and caregivers of those affected. I'm just going to super briefly mention a couple of ways that we, CMS, are thinking about this issue and we will turn it back to Meghan so we can spend most of our time really hearing from you. I want to mention that through our Center for Clinical Standards and Quality represented by Shari, Dr. Ling, here on the screen, we are considering how quality of care can be enhanced, to support people with dementia as well as their families and caregivers in ways that optimize healthcare outcomes across the continuum and our Center for Medicare represented by Doug Jacobs, we are looking at how to provide care to people with multiple chronic conditions including dementia, and we are looking at it through Medicare and wellness visits as well as chronic care management services, behavioral health integrations, and Medicare's cognitive assessment services. At the Innovation Center represented by Dr. Liz Fowler, we're exploring possible options for testing models for Medicare and dual eligible beneficiaries. Moving in, Tim Engelhardt (duals office), and making sure we are thinking about dementia, including Alzheimer's disease. We know what a big issue this is for the Medicare program, thinking about that with a long-term care services, but also from a Medicaid angle, also represented by Dr. Aditi Mallick. And thinking about that particularly with home and community-based services. So, with that, I will say what a priority this is across CMS as we think about what things we can do to move the lever. I look forward to hearing your thoughts. So, thank you. Back to you Meghan.

Meghan O'Toole: Thank you, Administrator. Now we will hear from our panelists on this important topic and the five questions. I want to remind panelists to keep your remarks to three to five minutes so we have time for everyone to speak. With that, I turn it over to our first panelists, Sarah Lenz Lock, Senior Vice President for Policy and Brain Health at AARP.

Sarah Lenz Lock: Thank you. It is my great pressure to talk with all of you today, and I am incredibly impressed with cross departmental cooperation as evidenced by this listening session and to many of you who devoted your career to improving health care across many different conditions, and the fact you are talking about improving care for services for people living with dementia is a huge testament to the importance of the topic and

how crosscutting it is across our health care system. The first question, what areas of whole person care for people living with dementia and their caregivers are most in need of transformation. I would say the first is diagnosis detection and screening. It is appalling that our system is so poor at it and many people take many years to determine whether or not they have a disease and can't get clear answers to the question, is this normal aging or is it dementia? And then if it is dementia, what kind of dementia we are talking about. People can get diagnosis of depression, a whole variety of issues, long before they get the answer to what is causing their cognitive issues. The second is, chronic care management. I heard you talk about that, Administrator, but when you think about dementia as a continuum of care in which the disease progresses, chronic care management looks very different at the early stage of the disease than it does at end of life. Thinking about chronic care management across the continuum and spectrum of what the disease looks like across the lifespan is incredibly important. I know my colleagues at AARP have spoken to you about the Medicare pilot on family caregiver support services. This is another important area. It is critical to transform how family caregivers receive the support they need to be a partner in care to their health care providers. Family caregivers are an essential part of the beneficiary care team including people living with dementia and other conditions. Treating the family caregiver as if they are a member of the team is as important as making sure there is a team-based approach to health care from the provider's perspective. AARP developed a pilot program in Medicare on family supported services to test family caregiver interventions for targeted Medicare beneficiaries. Can I suggest that those living with cognitive impairment would be a perfect place to test out that pilot program? The pilot would provide supported services to family caregivers based on a culturally inclusive assessment of the caregivers need to determine necessary supports. Perhaps many of you have heard me say that you need to ask the person living with dementia what is the outcome they want. In this instance, we need to ask the caregiver so what is the outcome they need in order to make sure the care they are providing for their loved one works. You asked in your second question how do you prioritize the domains of care? You give us three choices. All are important, but if there was one, I would say caregiver support and education. To build the team of dementia care services and effectively deliver services and make sure health care advice being given is able to be carried out. The pilot is voluntary for the Medicare beneficiary and family caregiver. A multi-state pilot would include Medicare beneficiaries representative of the overall Medicare beneficiary demographics and collecting demographic data and include an evaluation. I know I am running out of time, but I have to say what would make it appealing to people living with ADRD and providers to participate in a specialized model of care: include their caregivers in this conversation. A care navigator to stay with the person as their condition progresses so they can direct services that are available to people when they need them would be a very important and appealing part of creating a specialized model of care that would match the continuum of care that a person living with dementia has. Thank you again. I don't want to take up too much time. I will give the speaker back to you all.

Meghan O'Toole: Thank you Sarah. Next, we will turn to Susan Peschin, the President and Chief Executive Officer of the Alliance for Aging Research.

Susan Peschin: Can you hear me now? Sorry about that. Thank you to Administrator Brooks-LaSure and all of you at CMS for the invitation to share our insights today. There are three areas I would like to focus on and make recommendations related to the questions that CMS posed to us, and I welcome the opportunity to discuss any of these today or in future meetings. The first area is equity. We would like to see CMS and CMMI conduct a review of health outcomes among people with dementia in Medicare Advantage plans versus Medicare fee for service and would like you to look at this by race, ethnicity and socioeconomic status with a sub analysis on beneficiary groups who are dually eligible. The reason I'm asking for this, for the rest of you listening in is, Medicare Advantage plans use risk coding called hierarchical condition category codes, called HCCs, that help estimate future healthcare costs for patients in these plans. Such coding has been identified as discriminatory by some researchers in health policy because the risk score uses health cost as the measure of health need, and we know negative differences in access and utilization care exist in many communities of color. There is a 2019 study in Science that examined risk coding by Optum, and found black patients assigned the same level of risk are actually sicker than white patients. Bias occurs because the risk scores use health costs as a measure for health needs. According to the study, this bias reduced the number of Black patients identified for extra care by more than half. In 2020, CMS added two additional HCCs for dementia, dementia with complications and dementia without complications. Adding these codes may sound useful on paper, but CMS, we are asking you to explore claims data to discern if there is a difference in care and outcomes utilization for beneficiaries in MA versus fee for service. Second, in equity, is to incentivize and expand the program of all-inclusive for the elderly or the PACE program availability to ensure better access to much-needed home and community-based care services for beneficiaries with dementia. For those listening, PACE has been around a couple decades and it helps people with dementia meet health care needs in the community instead of going to a nursing home or other care facility. And there's a lot of services that PACE provides. They provide primary care, dentistry, home and hospital care, meals, prescription drugs, social services like caregiver training, medical specialties services, nursing home care, occupational physical therapy and others services as well. Beneficiaries report positive experiences with the PACE program, but only 60,000 beneficiaries are currently involved. I could not locate any breakdown in race or ethnic data. When I did look in the DMV area, there are no PACE plans in D.C. and only one in Maryland of which only 16.5% of the eligible population has access. In Virginia, there are 7 PACE plans and 62% of the eligible population has access. Learning from the success and making coordinated services available in a similar fashion for a wider array of diverse beneficiaries -- we would like that to be a priority. My second area of focus is on safety and our first recommendation is to please eliminate the federal waiver that allows states to require hospital patients recovering from COVID-19 to be transferred to nursing homes to convalesce. This practice was started at the beginning of the pandemic in March 2020 and it has to end because it has and continues to result in COVID-19 being transmitted within nursing homes, and it puts longer-term residents and staff at risk. We would also like to see transparency in data as to what happened as a direct result of these waivers since March 2020. HHS and CMS have done reviews in their own claims data that show people with Alzheimer's and related dementia have been disproportionately impacted by COVID-19 deaths and morbidity in our nation's nursing homes. And the second recommendation on safety

is to work with the FDA and Assistant Secretary for preparedness response at HSS to address the non-distribution of COVID-19 antiviral therapies to nursing homes and other long-term care settings. The FDA's emergency use authorizations prevent pharmacists from prescribing and this is a particular barrier in long-term care where the consultant pharmacist or long-term care pharmacist is the prescriber. This antiquated approach of testing at location one, seeing a doc at a different location, and obtaining treatment at a third location is slower and more burdensome. For people in rural and underserved areas with limited mobility, it is untenable and exacerbating inequities and disparities. There are 330,000 pharmacists and they're within 5 miles of 90% of the population. My third area of focus is on quality, and my first recommendation is for CMS and CMMI to work together to promote the relatively newer codes that were put in place program-wide to increase detection in care planning in the primary clinical setting. There is discussion about new models. Those are limited in scope usually, they are supposed to be. There are program wide codes, and we need to exhaust all efforts at trying to promote these and getting docs to do them before we start, or figure out why there hasn't been uptake. Research has consistently shown 50% of AD and other dementias go undetected in the primary care setting and claims data shows a lot of beneficiaries with dementia are identified, encoded with having dementia for the first time in hospital or even the nursing home. It is putting the cart before the horse to introduce new models in our field until you have exhausted these efforts. Our second recommendation is to consider testing and updated antipsychotics quality measure for nursing homes. There was a May 2021 HHS Office of the Inspector General report that found the current CMS antipsychotic quality measure fails to distinguish between appropriate and inappropriate use. The measure only reports percentage of residents who already use antipsychotics rather than identifying inappropriate use. We agree 100% with that report. Quality measurement needs to enable patients for whom antipsychotics are clinically appropriate, including those with serious mental illness, to do so and prevent prescribing for patients for whom it is clinically inappropriate. A better measure is going to ensure that CMS and surveyors are easily going to be able to cite and take action when prescribing is inappropriate. We will be sending comments on the 2023 proposed SNF (Skilled Nursing Facilities) payment regulation that describes this in greater detail. Thank you, appreciate the time.

Meghan O'Toole: Thank you. Next we have Matthew Baumgart, the Vice President of Health Policy, Alzheimer's Association.

Matthew Baumgart: Thank you very much Meghan and thank you to CMS for giving me the opportunity to speak to you on behalf of the Alzheimer's Association and thanks in general for holding this listening session. We greatly appreciate your interest in improving quality of care for people with dementia. I am going to talk but generally address questions 1, 2, and 5 on your list. We at the Alzheimer's Association believe both care delivery and reimbursement must be transformed in order to better support those living with dementia, their caregivers and clinicians. Whole person care is really critical because the needs of people with dementia are many and varied. They range from medical to social to long-term care, just a couple of illustrations. According to CMS' own data, more than 95% of individuals with diagnosed dementia have at least one other chronic condition. Many times, those kinds of conditions

complicate the management and care of the individual's cognitive impairment. You cannot view these conditions, you cannot treat these conditions in isolation from each other. It is even more than that because it is more than just health care. For more than any other condition, social support and caregiver support are crucial to the quality of care and quality of life for the person with dementia. It can be make or break. Unfortunately, the health care system too often fails to meet all or most of the unique needs of those living with dementia. That is why we believe CMS must develop, test and implement a comprehensive dementia care model to target whole person care. Such a model would involve a single source of care to meet the needs of persons with dementia based on satisfaction data of dementia care management programs tested to date. We believe it would be highly appealing to those living with dementia and their families because it helps eliminate the current fragmentation and inconsistent quality of care. Their needs are medical and psychosocial, the latter of which are often not covered by Medicare and more often not coordinated with medical care. It is a confusing maze that individuals caregivers have to navigate on their own and too often it results in poor quality services. That exacerbates co-occurring conditions. It is a vicious cycle. Other chronic conditions affect management of dementia and then the failure to properly manage dementia complicates an individual's other chronic conditions. Whole care is really important and we believe a dementia care management model would deliver critical services and be appealing to beneficiaries with Alzheimer's disease. In terms of domains, care coordination is at the root of a top notch model of care, from that caregiver support and education, as well as home and community based services, so it is difficult to separate and distinguish these domains of care because the former care coordination has to encompass the latter in order to work. I want to focus on caregivers. Sarah Lock talked a lot about this, but to reiterate, persons living with dementia and caregivers are often framed as a dyad. A dementia care model that accounts for and supports a caregiver, the caregiver is necessary and would frankly be an appealing selling point for participation, as Sarah mentioned. Beyond that I don't believe you can have success with management of care for a dementia patient without including caregiver support and education because of unique challenges a caregiver with dementia faces that are not usually faced by other caregivers. Finally, I'd like to say that we believe a dementia care management model with a restructured capitated payment system would be appealing to providers. The existing patchwork under fee for service is insufficient to cover the true cost of high quality dementia care. That is at its core why, even though these models demonstrated better quality care and lower cost of the sales system, they have not proliferated. It's not because people with dementia do not want it, they do, it's not because caregivers don't want it, they do, especially if they're included, it's not because providers don't want it, those who know and understand dementia care do. It's really because it is not financially viable under the current pay for service system to provide this dementia care management. The model we proposed at the Alzheimer's Association would reimburse providers on a capitated basis paying for value rather than volume, would vary based on complexity of patient's care, and then we propose providing an additional quality based incentive payment, and we think that would be appealing to providers in such a way as to enable more dementia care management to be provided in the system and available to more people with dementia. Thank you for holding this session and allowing me to address you today.

Meghan O'Toole: Thanks so much. Next, we will hear from Michael Cheek, the Senior Vice President of Reimbursement Policy and Legal Affairs at the American Healthcare Association.

Michael Cheek: Good afternoon everyone, and thank you for your time today. This is an important issue to me both personally and professionally. I interviewed several of our providers representing assisted living and in nursing facilities, and they asked me to focus on a shift from fee-for-service to alternative payment models and managed care. As we move into that arena and away from fee-for-service, their view is maintaining important elements from traditional models is important such as neutral third-party case management or care coordination. In 1915C home and community-based waivers, the care coordination function has to be separate from the provider. This is particularly important for family caregivers that may be distressed from delivering care and individuals with Alzheimer's and related dementia whose decision-making should be impaired. As we move into accountable care models and managed care models, having an independent entity that can serve as something like an Alzheimer's disease and related dementia ombudsman-like function could be important to ensure the needs of the individual are being represented along with the needs of the family caregiver. That is an important point. An additional piece to think about as we move into a broader array of different types of payer arrangements and care delivery arrangements is, to think about how elements in existing Medicare Advantage arrangements could be considered. What sort of supplemental benefits with Medicare Advantage plans could be expanded to support family caregivers who have relatives and loved ones with Alzheimer's disease and related dementias. Also, there has been an array of chronic conditions special needs plans focused on dementia. Several of them have not been successful. In understanding why those chronic condition on special needs plans that focused on Alzheimer's disease, were not as successful as others, could be important in terms of finding ways and coordinating strategies, and other broader approaches to Alzheimer's and dementia care. Some of those arrangements could be useful for provider led special needs plans and population health management arrangements which we have been focused on heavily. Another element associated with this in terms of the specialized model of care are moving to the last piece, focusing on cultural competency and understanding the roots of someone's life and culture both in language, how information is conveyed and the care delivery environment, both for the provider and any third-party payer that providers may be working with. Also understanding the payment amounts and how it's made related to the previous speaker's comments. Value-based reimbursement as well as shared savings to incentivize care that is truly tailored to individuals with Alzheimer's and related dementia are important for providers to drive the behavior that I think CMS would want to see as well as the experience persons with Alzheimer's disease and related dementias would want to experience as well as their family caregivers. Again, with family caregivers, understanding their needs are as important in the same ways as the actual individual in making sure that the plan or accountable care entity that CMS may be considering going forward, offer those same sort of supports. 1915C waivers often offer robust family support, caregiver family support benefits in the waiver, so those might be elements to consider as well. I appreciate the time. I would be

happy to speak further, and I will list providers that specialize including adult data to put the team in touch with. So, thank you.

Meghan O'Toole: Thank you. Our next panelist is Laura Trejo, Executive Director of Aging and Community Services for the L.A. County Department of Workforce Development, Aging and Community Services. Laura?

Laura Treja: Good afternoon everybody and thank you for this opportunity. Thank you for this incredible timely discussion with all of us. I want to echo what previous speakers said. If we are looking at a moment of transformation, that moment will be when we consider Alzheimer's and their family caregivers as a dyad, and interventions have to reflect the opportunities for families to be served as a team. In my over 36 years of experience working with families in LA, I have seen that repeatedly. When we ignore the important elements of the care and support family members provide, we are not able to help the older person experiencing dementia to the degree it is possible. I want to have you think about, how do we begin to develop funding mechanisms that support -- for example, I remember having to advocate with all of you many years ago with HRSA and other state and federal agencies the importance of respite care. Because respite was always looked as a secondary impact to the client. I am here to tell you it is not, it is a primary effect to older persons experiencing dementia when their loved one is not receiving the level of support and relief from the day-to-day care of working -- caring for someone 24/7. I see respite as a missing link in the work we are doing in the reimbursement mechanisms available. I have seen almost a disappearance in our state of respite resources, which I think is alarming. In Los Angeles County, we are looking at Alzheimer's as the second leading cause of death. That tells me the needs in the community are much greater than resources available and a lot of it has to do with funding strings. If mechanisms for reimbursement are not available, services disappear in communities. I want to ask you to think about how to develop models that will serve this emerging crisis we are facing in communities caring for persons with dementia. The other thing that I think is critical is, how do we begin broad dissemination of evidence-based programs that allow for care coordination, really educating and empowering families to make decisions on a timely basis when they are needed. For example, there are an existing suite of evidence-based programs that are ready to be implemented, but it seems the time lag between their readiness and our ability to get reimbursement seems to drag for many, many years. That is a disservice to our communities. Let's think about ways to streamline those interventions. I also believe in caregiver education, it continues to be not reimbursable, but it should be. Families need to understand that dementia, dementing disorders are not a normal part of aging. Yet I work with aging communities every day here in Los Angeles from diverse backgrounds who many do not have equal access to information to empower their decision-making in caring for loved ones. That is something we need to make major federal investments in ensuring we are educating and making information readily accessible and available to the diverse communities experiencing dementia. In Los Angeles that is a challenge. We have 12 threshold languages and over 90 languages spoken in our school system. We have to think differently about how we are developing those resources for families. We have to come up with national level campaigns that support our communities. I have not seen one of those in a long time when it relates to dementia, Alzheimer's, or anything related to these conditions. It is time because our communities are

emerging, growing rapidly and the lack of information and resources is alarming to me. I look forward to engaging in a discussion with you. Please feel free to reach out to us. Thank you for this opportunity and for thinking about this timely and important topic. Have a great rest of your day.

Meghan O'Toole: Thank you Laura. Our next panelist is Dr. Malaz Boustani, who is the Chief Innovation and Implementation Officer from the Center for Health Innovation and Implementation Science at Indiana University.

Dr. Malaz Boustani: Thank you so much Meghan, and thank you all for serving our most vulnerable Americans. I'm a geriatrician, so I'm still serving people in the front line every Monday, and I have been working on dementia care transformation for 20 years. I have unfortunately been thinking I need to break the 17 year cycle from discovery to delivery and our model that worked in 2006 and published in JAMA got promoted from that. It is now 16 years, and I have not been able to deliver it outside of our safety net health care system in Indianapolis where, thank God we are still serving 50% African-American dual eligible, but we have not been able to grow it outside a small spot in Marion county because of lack of demands for our services. I have not been able to deliver it to my father in law, who lives 5 hours south in rural Kentucky in his last six months of life he ended up in the hospital every month. I thought he might be listening to me, but I was the wrong messenger. I want to share and talk about questions 1, 2, and 5. The answers to these three questions will solve the issue of equity because we have done it in our safety net healthcare system. The problem has been growing because of limited resources. We were able to deliver it despite lack of reimbursement because we have an amazing community behind us that is working hard, but that's not always available. Here is my primary response -- you heard this from another speaker. We published a paper, a blueprint for alternative payment models to support widespread implementation of evidence-based collaborative comprehensive dementia care model. Not just our group in Indiana University, Indianapolis have developed this, but now multiple innovators across the country and world in Germany, who developed this comprehensive dementia care model that helps not just patients with Alzheimer's disease and unrelated dementia, but they are unpaid most of the time, their family caregivers, their spouse, faces a similar high level of stress and burden and ironically, their overall mortality rate goes up because of their caregiver task. A randomized controlled trial, four or five of them already, and multiple demonstration project across the U.S. have confirmed without doubt the effectiveness of this comprehensive dementia care model. It helps the patient and the unpaid caregiver. The way this comprehensive dementia care model works, it is managing the cognitive, functional, behavioral, and psychological need of the disability of a patient living with Alzheimer's disease and other related dementia. It also prevents and manages the burden of their unpaid caregiver, does a lot of coordination of care transition and services among providers and community resources. Not just in the primary care system or hospital, but in the home and community-based services. Finally, it is work on advance care planning, and shared decision-making through this dyad. Unfortunately, like we witnessed over in Indianapolis, the current healthcare system, it has failed to implement this model in a scalable, sustainable way because the current system of reimbursement does not adequately support delivery. These patches that have been tried, to attempt volume-based care, has not created

such demand. There is a lot of complexity in the primary care system cannot deliver, there's not much demand for it. My suggestions in our group, our research suggests, in order to meet the needs of our most vulnerable people and given the overwhelming evidence of effectiveness, not of efficacy, of this collaborative comprehensive dementia care model, it is crucial to create an appropriate payment system that acknowledge what you already heard: the role of the unpaid caregiver and also allow the provider to coordinate managed care for both the patient living with Alzheimer's disease and their family caregiver or unpaid caregiver. We think the restructuring of CMS payments can meet the need of a person with dementia and their unpaid caregiver. We can think this can be done by implementing through per beneficiary, per month payment for services for community living beneficiary with Alzheimer disease and their unpaid caregiver. For more details I think we can work with you on how to execute the -- those details. I think the Alzheimer's Association has substantial experience in understanding this alternative payment model and we can collaborate with AARP to do the same thing. But if you don't do the comprehensive dementia care model, early detection of Alzheimer's disease might cause more problems than benefits. I tried to do it in a hospital setting when I tried to improve early detection of Alzheimer disease in the hospital. All I got out of, because I did not have the comprehensive coupling system, higher people using anti-psychotic and they stayed in the hospital longer. I recommend that you need to couple early detection of dementia with comprehensive collaborative care model. Without it, there are more unintended consequences than positive consequences. If you need help with that, let us know. You have been doing it anyway. You have been doing a lot of demonstration projects, you have an amazing innovator in CMS, you have Julia Tritton to give you insights from the frontline. Right now is the time. I really don't want my wife, who is at high risk of developing Alzheimer's disease and other dementia, not to optimize her quality of life. Thank you so much for everything you do. I appreciate it.

Meghan O'Toole: Thank you so much. Our next panelist is Nora Super, who is the Executive Director of the Milken Institute Center for the Future of Aging. Nora?

Nora Super: Great. Thank you for inviting me to be here today and speaking along with my esteemed colleagues working on these issues for many years. As the Administrator said in opening comments, health care is personal, so I wanted to start by telling a personal story. My father, a medical doctor, was diagnosed with Alzheimer's disease when he was 78 years old. As most people living with dementia do, my dad had multiple conditions treated by a variety of specialists, paid for by fee-for-service Medicare, most of whom did not take into account his dementia diagnosis when prescribing treatment. He was often hospitalized, especially in the later stages of his journey, because he was no longer verbal, and could only describe his pain by crying or screaming. One particular episode sticks in my mind and drives my passion for my work. One day after he had been hospitalized for acute pancreatitis, the discharge nurse called my sister to say, you need to come get your dad, he is being discharged. Sorry – upon- my sister, in the middle of a workday, she had two young children and could not drop everything to come to the hospital. She pleaded with the hospital, a University medical center, to keep him until 5:30 p.m. so she can make arrangements to pick him up. They told her no, they needed the bed. When my sister arrived a few hours later, she found her father, who used to be the Chief of Psychiatry

at a major public hospital, alone in a wheelchair in a hallway where he had soiled himself and was crying. I share this story not to criticize hospital staff who are understaffed and following orders from management. I share this because this happened to my family, even though my dad was a medical doctor, and my sister and I both worked in the health care sector. Unfortunately, this is one of the indignities and frustrations we encounter while trying to help my dad navigate complex health and long term care system during his journey with dementia. If I, a white, middle-class well educated woman could not get the care he deserved, what about those nonwhite, low income, unable to speak English? I shudder to imagine. The Milken Institute launched the Alliance to Improve Dementia Care in July 2020 to transform and improve the complex health and long-term care systems that people at risk for and living with dementia must navigate. The alliance sits at a unique intersection of the nonprofit public and private sectors, enabling the engagement of nearly 100 stakeholder organizations, many who are represented in this listening session from health systems, industry, research, advocacy, philanthropy, community-based organizations, government, and people living with dementia and caregivers. The growing prevalence of dementia creates an urgent need to reform care of delivery. As the U.S. population ages, our risk of developing dementia doubles every five years after we turn 65. Our research determined 7.2 million Americans today live with Alzheimer's and other dementias and we expect that number to double over the next 20 years with women and underserved communities being disproportionately impacted. In November last year we released a report scaling comprehensive dementia care models which outline recommendations the Milken Institute developed in collaboration with leaders across multiple sectors. The recommendations focus on improving post-diagnostic care and payment policies under traditional Medicare, where we believe there is the most urgent need for reform. In answer to question one, we agree wholeheartedly with what Dr. Boustani just said. There is a lot of evidence that shows a conference with dementia care models can improve health outcomes, reduce cost, and support caregivers, but adoption has been slow due to wide-ranging needs of those living with dementia, the need for robust workforce training and equitable access to health care, misaligned incentives and inadequate payments. To scale these models and make them accessible for all Medicare beneficiaries, the alliance recommended five high-potential action steps in our paper and I encourage you to read it at a later time. Due to the limited amount of time I have to speak, I will focus on the payment recommendation. The alliance to improve dementia care recommends adopting an alternative payment methodology to reimburse providers for comprehensive and dementia care, using a value-based payment model. We have worked in collaboration with the Alzheimer's Association, AARP, and several prominent geriatricians such as Dr. Malaz Boustani and Dr. David Rubin to describe the eight core elements of comprehensive dementia care. We propose moving away from the traditional fee-for-service payment structure and towards a capitated payment in which providers receive a monthly, per beneficiary fee based on the individual's needs in case complexity. The need to move forward is urgent. Alzheimer's disease and related dementias could bankrupt the Medicare and Medicaid systems unless we adopt new ways of delivering care. When choosing the domains of care, as Sarah and Matthew noted, it is hard to choose. We think care coordination is an essential first step for those living with dementia to receive high-quality comprehensive care. We believe a comprehensive dementia care payment model with a

care coordinator at its core would be appealing to both providers and people living with dementia and their caregivers because incentives would be aligned (among payers, providers and patients) and ensure those living with dementia and their caregivers receive more seamless, coordinated help and long-term care. Thank you for your time.

Meghan O'Toole: Thank you Nora. Our next panelist is Dr. Shekinah Fashaw-Walters, who is the Assistant Professor of the Division of Health Policy and Management at the University of Minnesota.

Dr. Fashaw-Walters: Hello, thanks so much. I'm Shekinah Fashaw-Walters. Thank you for the invitation to share some thoughts and insights with you all today. My heartbeat and focus as a researcher will always be advancing health equity. It is with that lense that I speak to you today, hoping to address questions 2 through 4 for you. When I think about improving health outcomes, prioritizing all three domains of care, care coordination, caregiver support and education, and home and community-based services is what I see as being key to improving health outcomes, creating promising practices and making specialized models of care not only appealing, but accessible to people living with dementia and their caregivers. We know from the literature that people living with dementia are more likely to receive lower quality care in nursing homes. From some of my work, we see that antipsychotic use and schizophrenia diagnoses remain an issue of concern within nursing homes, especially for black nursing home residents with dementia. The majority of older adults prefer to age within their homes. We also see in literature that black caregivers are more likely to have issues of coordinating care. Based on this evidence, it is imperative to take a multilevel, multipronged approach to improving outcomes of care for people living with dementia and their caregivers. In other words, we need to make sure home and community-based services are accessible, the high-quality services are accessible. That care is coordinated across providers and caregivers are empowered and educated. We can't leave any pieces of this out. It is important to note, improving care does not stop at these three domains. We have to consider the larger systems that give rise to these care inequities. If I had to choose one area to prioritize today, keeping health equity in mind, very similar to my fellow panelists I would choose caregiver support and education. My reasoning for that, is several studies have shown caregiver education to be identified as one of the greatest challenges in areas of need for black communities specifically, including black immigrant communities. The immigrant memory collaborative, which is focused on African immigrant populations, a doctor and her colleagues identified the terms dementia and caregiver are not used in the same ways across communities. This has prompted the need for cultural adaptations to provide the appropriate and relevant information to these communities. Another example of a promising and growing developing intervention is one by Dr. Epps and her colleagues that piloted an online education program called Caregiving while Black. It is a well sought-after program in Georgia, and this tailored intervention puts tools and resources in the hands of black caregivers to help them manage home life, embrace self-care for themselves, and navigate the health care system. That is, how do they deal with the doctor visits, what documents do they need to have in hand, what questions they should be asking. On a similar note, it is important people living with dementia and their caregivers receive good information on available resources. Right now, people living with dementia and their caregivers may go to their AAAs, clinicians,

family, friends, may even community organizations for information and resources. This points to the importance of making sure the community is well informed about existing resources. To point to another existing and promising intervention, we are doing work in Minneapolis through our Center for Healthy Aging and Innovation where we are implementing an intervention developed by Dr. Epps called ALTER. ALTER focuses on equipping black church communities with information and resources to support people living with dementia and their families. It is our hope people would use official sources of information such as CMS Care Compare, however public reporting of quality information but it could use improvements as you've seen in the literature. I would imagine it might be more helpful to have publicly recorded quality information specifically for people with dementia so they and their health caregivers can make more tailored, pinpointed decisions about their care. This work to improve care and advance health equity for people living with dementia is not easy, but I hope I have given some examples of work that is in progress and maybe spark new ideas and considerations for you all today. Thanks again for convening this session and for having me here.

Meghan O'Toole: Thank you. Our last panelist, but certainly not least, is Gretchen Wartman, Vice President for Policy at the National Minority Quality Forum.

Gretchen Wartman: Thank you for the opportunity to present and to bat cleanup I think. I want to thank all of those who presented prior to me because I would say I agree with everything that has been said, and they addressed specific aspects of the questions that have been presented to us. I would submit that for a number of reasons, CMS as it relates to care for those with Alzheimer's disease and related dementia, has an extraordinary opportunity here to be truly innovative and creative given the challenges of the baby boomer cohort aging into Alzheimer's disease, given the realigning of the racial and ethnic demographics of the population, given those and communities of color becoming a collective majority of this country are at higher risk for Alzheimer's disease than our Caucasian, non-Hispanic populations. Given as others have spoken to, the increased economic and social burdens of caregiving for these same populations. I would speak to two issues before my recommendation, that models that tend to be employed by CMS focus to a significant degree on mitigation of financial risk versus mitigation of patient risk. There is a unique opportunity to yes, recognize that creating cost efficiencies in care is essential for everyone, but putting mitigation of patient risk at the center of this conversation is one of those unique opportunities that CMS can embrace at this moment. Another issue that continues to be advanced is the notion that somehow, the caregiver community is ancillary to or supportive of a caregiving process that centers on the clinician. I would submit that there is an innovative new model that the caregiver be recognized and precedent to, concurrent with, and post hoc to the clinician-specific engagement, so that then brings to the caregiving conversation a more holistic approach and the potential to assign value to the caregiver that has often been referred to here as the unpaid caregiver. What's also not spoken to is that it tends to be the women in the community that are unpaid that bring to that caregiving experience or that burden of caregiving, all of the other responsibilities that women have in society. I would ask that CMS take the time to design a new kind of model that enables the information that the family, the caregiver can bring before the patient is diagnosed by the clinician. The information that their caregiver can bring that would enable earlier identification of the dementia process rather than

what's being labeled normal aging, so that we can advance earlier diagnosis, so we can bring those patients into the pool of information that informs care guidelines and research. So that earlier identification of a dementia process takes burden off the family that are providing care before the patient has received a diagnosis. This I would ask be considered as Alzheimer's disease and related dementia "stage shifting initiative" that pulls all into that risk mitigation conversation. And I'm looking to ask one more thing. My understanding, and I'm assuming it may be true here, is that these accountable care or payment models are exempted from the common rule. I don't know if that exemption is a legal requirement or if CMS has an option to employ the common rule in engaging with these families and patients and communities as it moves forward. I would ask it consider doing so. Particularly given the populations who are at significantly, disturbingly, higher risk of this diagnosis, and the compromised financial and health experience to their families. I will stop there. Thank you so much.

Meghan O'Toole: Thank you to all our panelists and everyone listening in today. A reminder you can send any comments you would like to share with CMS on today's session to CMMIstrategy@cms.hhs.gov. Now back to the Administrator Brooks-LaSure for closing remarks.

Chiquita Brooks-LaSure: Thanks Meghan. I also put your email into the chat so if anybody wants to send resources they talked about today, please send them to Meghan. You can get them to me and the rest of the team represented on the call. I want to say, knowing we're over time, how much we really appreciate such a rich discussion. Thank you so much for sharing your perspectives. The team knows, we take seriously what we hear. We will be incorporating the things you shared with us into our decision-making. We really appreciate hearing from all of you, particularly those of you sharing your own personal experiences. Thank you so much and please enjoy the rest of your day.