



# Payer Recommendations

## Dementia Care Virtual Summit Meeting

July 2020

Prepared by:  
**Payer Stakeholder Group**

Additional information can be found at the Summit website (<https://www.nia.nih.gov/2020-dementia-care-summit>) or the National Alzheimer's Project Act website (<https://aspe.hhs.gov/national-alzheimers-project-act>). The opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of HHS, the contractor or any other funding organization.

# **National Research Summit on Care, Services and Supports for Persons with Dementia and their Caregivers**

## **2020 Dementia Care Virtual Summit Meeting: Payer Stakeholder Group Research Recommendations**

### ***BACKGROUND***

The 2020 Dementia Summit Payer Stakeholder Group was asked to develop research recommendations related to how payers make coverage and related decisions for Medicare Advantage members living with dementia and their care partners. The group held calls monthly beginning in September 2019. We decided to divide the landscape of payers between government-operated fee for service programs serving individuals with dementia and those administered by private health plans. For government administered programs, the Centers for Medicare and Medicaid Services (CMS) and the U.S. Department of Veterans Affairs (VA) each began the task of describing the services delivered through Medicare and VA respectively as well as the authorities under which those services are authorized.

For the purposes of this summit and given the capacity and resources of the group, those services delivered directly by states on a fee for service basis under Medicaid as well as those services offered through employed groups through health and supplemental benefit programs were excluded from our research. Please see Appendix B for Payer Stakeholder Group members.

Consistent with the work done by the payer subgroup for the 2017 Summit the group agreed to design and conduct interviews with a cohort of payers representing Medicare Advantage (MA), including duals special needs (D-SNP) and Medicare-Medicaid (MMP) plans and Medicaid Managed Care plans including those that deliver managed long-term services and supports (MLTSS). We held calls regularly to review training materials and interview survey questions.

### ***STRATEGIC APPROACH***

The Payer Stakeholder Group discussed a strategic approach on initial conference calls. In particular, conversations focused on which payer types were most important to interview first, how to design survey questions and conduct interviews and how to code and summarize interview data into a set of actionable recommendations.

The Health and Aging Policy Fellowship (HAPF) Program (<https://www.healthandagingpolicy.org/>) brings mid-career geriatric professionals together to learn more about local, state and federal aging policy. A number of Health and Aging Policy Fellows (HAPFs) expressed interest in volunteering to conduct payer

interviews between November 2019 and early January 2020, in order to learn more about payer perspectives in care of individuals living with dementia and their care partners. Six fellows ultimately volunteered to participate as interviewers. Most had research or clinical experience and had conducted and/or coded interviews previously.

The Summit team developed written interview tools and protocols, and standardized interview survey questions were developed collaboratively by the team along with expert input. Individual or group training calls were held with the fellows, and all interviewers received the same guidance and protocols. Interviewees were each given a site number and were assured that the identity of the organization would not be revealed. Interviews were recorded and transcribed, and notes were submitted as well. Coding was done by the fellows, and a second round of confirmatory coding was completed for each interview. Main theme and sub-theme coding were compiled into an Excel spreadsheet and reviewed by the group co-chairs (Goodman, Bonner).

## ***RECOMMENDATIONS***

The recommendations below include feedback from senior representatives of plans delivering care to people with dementia through Medicare and Medicaid (including MA, D-SNP, FIDE-SNP, MLTSS and MMP plans) as well as recommendations from the Payer Stakeholder Group. Recommendations were summarized by the Payer Stakeholder Group and submitted to the Summit Steering Committee in January 2020.

### **General Research Recommendations from the Payer Stakeholder Group**

**Recommendation 1: Research and analysis should be conducted to increase understanding about how various types of payer organizations make decisions about the dementia-related care, services and supports they will provide and the kinds of research findings that would help them make these decisions.**

Various types of payers differ in how they make decisions about the care, services, and supports they provide and the factors that affect their decisions. The Payer Stakeholder Group recommends that research and analysis about decision-making processes should be conducted as soon as possible with all types of payers that provide or could provide any of the many kinds of care, services, and supports needed by individuals living with dementia and their care partners. Such payers include organizations that pay for medical care; in-home, community-based, and residential care; and integrated care. Findings resulting from this recommendation will help researchers and research funders understand the decision-making process and identify research topics that are relevant and meaningful to payers.

**Recommendation 2: Identify methods to effectively engage payer organizations in research related to dementia-related care, services, and supports.**

The Payer Stakeholder Group recommends that research should be conducted leveraging ongoing work to engage stakeholders in the dementia care space to identify best practices in engaging payer organizations as a group in the development and adoption of best practices in the care of persons living with dementia and care partners.

**Research Recommendations from Medicare Advantage Plan Interviewees about the kinds of research findings that would help them make decisions about the dementia-related care, services and supports they will provide.**

**Recommendation 3: Conduct further research on health professional education for identification, detection/screening, treatment and management of dementia and related behaviors.**

A number of payer interviewees emphasized that while some members of certain health professionals (physicians, nurses, social workers, pharmacists, care managers) have expertise in care coordination and working with complex older adults living with dementia, others in those same groups as well as other types of clinicians (including, but not limited to, those working in emergency departments as well as paid caregivers at home and in assisted living environments) may lack adequate skills. Gap analyses to determine the skills and knowledge health professionals possess and the design and implementation of effective educational programs to fill the gaps was recommended by several interviewees. It should be noted that committee members also recommended research into the structural barriers that limit the ability of well-trained individuals to work effectively and utilize the skills for which they have been trained would be equally valuable.

**Recommendation 4: Conduct further research on how best to educate and support care partners of individuals living with dementia to prevent care partner burnout.**

This was a common theme mentioned in almost all the interviews. Payers recognize the tremendous need to support care partners of individuals living with dementia, and the limited resources for care partner support at this time. Recommendations included research into the effectiveness of caregiver support in early vs. moderate vs. end stage dementia; research into the use of supportive housing as respite for caregivers, and research into the accuracy of assessment tools for caregiver satisfaction.

**Recommendation 5: Conduct further research on the benefits of earlier advance care planning with individuals who are living with dementia and their care partners.**

This was another common theme -- that earlier attention to advance care planning could prevent adverse events and unnecessary or unwanted care in the future. Payers in many cases have developed protocols to promote advance care planning for individuals living with dementia but require resources to monitor the reliable implementation of this intervention.

**Recommendation 6: Conduct further research on the impact of addressing social determinants of health on quality of life and other health outcomes for individuals living with dementia and their care partners.**

Several payers noted that while their plans are attending to social determinants of health, these interventions are not specifically tailored to the needs of individuals living with dementia and their care partners. Rather, they are designed to be available to all plan enrollees who require them. Interviewees recommended research into the potential return on investment of dementia-specific interventions in these areas.

Interviewees frequently mentioned a lack of adequate and affordable transportation, food insecurity, inability to get to the grocery store or pharmacy. In particular, there was a belief that these types of interventions could positively impact care partners, reduce stress and slow care partner burn out. Studies that measure effectiveness of these programs including the length of time as a care partner when social determinants of health are addressed would be helpful.

**Recommendation 7: Conduct further research on earlier cognitive and functional assessment, including studies to determine whether earlier assessments lead to differences in health outcomes, disease trajectory, or care partner stress/burden.**

Studies by the Lewin Group and others have reported that the relative risk of being in the top 5% of health care spenders increases significantly with functional impairment (needing assistance with one, two or three activities of daily living (ADLs) compared with multi-morbidities alone). In addition, work by the Alzheimer's Association and dementia centers has revealed that involving someone with early dementia or cognitive impairment in care planning enables him/her to help make decisions that are consistent with his/her wishes, goals and life plans. It can also reduce care partner stress and burden and promote longer tenure in the community for the dyad (person living with dementia and care partner).

Several of those interviewed noted the need for research in this area as well as research into the accurate assessment of caregiver satisfaction and direct

assessment of patient satisfaction e.g. not an assessment of the patient's satisfaction based on information communicated by and through the caregiver.

### **Additional Research Recommendations from the Payer Stakeholder Group**

**Recommendation 8: Conduct further research on what services state Medicaid programs offer to individuals with dementia and their care partners and how those programs make decisions regarding coverage.**

The Payer Stakeholder Group agreed that, while critically important to understanding the scope of services available to people with dementia and their care partners, they lacked the capacity to conduct a 50 state assessment of state Medicaid program coverage for dementia care services. In addition, a number of interviewees reported that the Medicaid programs in the states in which they operated provided some services for individuals with dementia, but the scope of the resources provided were insufficient to deliver care effectively in the community to an individual with dementia in absence of the full-time support of an unpaid care partner. As a consequence, many care partners have left their jobs/careers or spent their own retirement savings or their children's college funds in order to stay at home and care for someone living with dementia.

**Recommendation 9: Conduct further research on how employers make coverage decisions for their retirees living with dementia and employees who are dementia care partners.**

An assessment of which employer-sponsored health and supplemental benefits are offered to employees with dementia and employees who are family care partners of individuals with dementia was outside the scope of this study. The Payer Stakeholder Group noted that multiple business groups and individual employers across states are exploring how better to support care partners who are still employed, trying to balance work and caregiving. In addition, businesses are working with health plans to determine how to support retirees living with dementia as well as current employees with various health needs. As the population continues to age, and numbers of individuals living with dementia continues to increase, this becomes a vital issue to address. The Payer Stakeholder Group recommends that research be conducted to understand better the scope of these benefits and potential programs and interventions that the employer community could offer to improve care for employees and retirees.

## **Appendix A: Survey Questions**

### **Developed by the Summit Payer Stakeholder Group**

#### ***Questions for All Payer Types: Medicare, VA, Medicare Advantage, MMP, SNP, MLTSS (current and planned offerings):***

1. How does your organization determine what dementia care services, supports, equipment, and products you will cover for people with dementia and their unpaid caregivers? Examples: results from clinical trials and studies; consumer demand; provider requests; other.
2. What kind of data or evidence do you need in order to make determinations regarding the types of dementia services, supports, equipment, and products you will cover?
3. If evidence of improved clinical or cost outcomes are used to make coverage determinations, what quality measures would you consider essential?
4. How does your organization determine which provider types can provide covered dementia care services and supports?
5. In 2017, interviews conducted with health care plan representatives, the following recommendations were made for future research topics. Would research on these topics be valuable for your organization in making coverage decisions?
  - a. Effectiveness and cost savings associated with training and support for unpaid caregivers.
  - b. Effective training for clinicians to identify and diagnose dementias.
  - c. Effective methods of supporting caregivers.
  - d. Effective methods for preventing or delaying cognitive decline and dementia.
6. Are there any important research topics that have not been listed here?
7. What quality measures do you use to measure the health, functional status and quality of life of people with dementia and their unpaid caregivers?
  - a. If none, are there specific measures, measure concepts, or areas for measurement that you believe would be meaningful to your organization?
8. Is there room for a value-based payment (VBP) in dementia care, where payment is linked to quality and outcomes?
  - a. If yes, what quality measures would you use?
9. If so, what VBP models would be appropriate contracting with providers of dementia care:
  - a. Bundled payment/episodes of care?

- b. Performance based payment?
- c. Accountable care organizations?
- d. Population-based payment (total cost of care)?
- e. Dementia health homes?
- f. Other \_\_\_\_\_?

**Questions directed only to Medicare Advantage, Dual Special Needs Plans (D-SNP), Fully Integrated Dual Eligible Special Needs Plans (FIDE SNPs), Medicare-Medicaid Plans (MMP), MLTSS Specific Plans**

1. How does your plan's coverage determination process differ from that of commercial insurance?
2. Other than a state or the federal program covering certain services, what else would be determinative in deciding whether to include dementia services and supports?
3. What specific unpaid caregiver benefits has your plan instituted?
4. Has your plan targeted unpaid caregivers of enrolled beneficiaries diagnosed with dementia for caregiver services? Which ones?
5. Are there financial caps within specific benefits, or are beneficiaries required to pay, in part for benefits?
6. Have plans seen cost savings related to offering dementia-related services? Can you describe?
7. What factors do Medicare Advantage (MA) plans consider when determining what services to offer as supplemental benefits?
  - a. How, if at all, has that changed with the new Medicare Advantage Benefit Flexibility offered by CMS?
8. How will MA plans determine who will receive the additional benefits? Who do plans look to for a decision regarding additional benefits?
9. Will the addition of dementia to the MA risk adjuster affect what you will offer?
10. What caregiver-specific services, if any, are offered by your plan?
  - a. Does your plan offer caregiver-specific models of care?
  - b. If yes, do those models identify and stratify members and their caregivers?
  - c. If yes, do they do so on the basis of need? Some other basis?

11. What innovative services, supports, and treatments have diverse payers instituted/delivered to people that result in savings, improved quality of care, and consumer satisfaction?

## **Appendix B: List of Payer Stakeholder Group Members**

### ***Co-Chairs***

Elizabeth Goodman	AHIP
Alice Bonner	Johns Hopkins University School of Nursing

### ***Members***

Shari Ling	Centers for Medicare & Medicaid Services
Jennifer Egan	Centers for Medicare & Medicaid Services
Ellen Blackwell	Centers for Medicare & Medicaid Services
Debra Cherry	Alzheimer's Los Angeles
Soo Borson	University of Washington
Michael Monson	Centene Corporation
Robyn Stone	Leading Age
Helen Lamont	U.S. Department of Health and Human Services
Katie Maslow	Gerontological Society of America
Susan Cooley	U.S. Department of Veteran's Affairs