

RECOMMENDATIONS

FEBRUARY 2021 • MEETING THE CHALLENGE OF CARING FOR PERSONS LIVING WITH DEMENTIA AND THEIR CARE PARTNERS AND CAREGIVERS: A WAY FORWARD

Recommendation 1: Implement and evaluate outcomes for collaborative care models in multiple and varied real-world settings under appropriate conditions for monitoring, quality improvement, and information sharing.

To enhance the evidence base for decision making about the implementation of collaborative care models—which use multidisciplinary teams to integrate medical and psychosocial approaches to the care of persons living with dementia—agencies of the U.S. Department of Health and Human Services (HHS) should work with state Medicaid programs and health care systems to implement these interventions and evaluate their outcomes in multiple and varied real-world settings under appropriate conditions for monitoring, quality improvement, and information sharing. Along with adding to the current evidence for effectiveness, these efforts should include examining key factors that are important for determining whether and how to implement an intervention, such as identifying workforce and space needs, testing payment models and integration into workflow, and ensuring adaptations for different populations (e.g., racial/ethnic groups) and settings (e.g., rural areas). Specifically, to advance these efforts:

- The Centers for Medicare & Medicaid Services should explore the value of collaborative care models offered as a benefit through Medicare Advantage programs and alternative payment models and for fee-for-service beneficiaries to build the infrastructure, train the workforce, and redesign the workflows that would facilitate the adoption, monitoring, and evaluation of these programs.
- State Medicaid programs serving persons living with dementia and dual-eligible beneficiaries should encourage participating health systems, systems that provide long-term services and supports, and managed care organizations to provide collaborative care for persons living with dementia. This care could be included in a dementia-focused quality metric.
- The National Institute on Aging, HHS's Office of the Assistant Secretary for Planning and Evaluation, the Agency for Healthcare Research and Quality, and the Administration for Community Living should support research and stakeholder engagement focused on collaborative care models to aid in scaling and sustaining the models; identifying monitoring and evaluation standards; developing monitoring and evaluation plans; and sharing information about key findings, lessons learned, and promising practices.
- Health care systems, including those in the U.S. Department of Veterans Affairs, should support infrastructure that would facilitate the collaboration of providers of primary care, mental health and other specialty care, and long-term services and supports within the health care system and with local home-based community services and support agencies in implementing collaborative care models to improve the well-being of persons living with dementia and their care partners and caregivers.

Recommendation 2: Implement and evaluate outcomes for REACH II and its adaptations in multiple and varied real-world settings under appropriate conditions for monitoring, quality improvement, and information sharing.

To enhance the evidence base for decision making about the implementation of REACH II and its adaptations—a multicomponent intervention that provides support for family care partners and caregivers—agencies within the U.S. Department of Health and Human Services (HHS) should work with state agencies, community organizations, and care systems to implement and evaluate outcomes of these interventions in multiple and varied real-world settings under appropriate conditions for monitoring, quality improvement, and information sharing. Along with adding to the current evidence of effectiveness, these efforts should include examining key factors that are important for determining

whether and how to implement an intervention, such as identifying workforce and space needs, testing payment models and integration into workflow, and ensuring adaptations for different populations (e.g., racial/ethnic groups) and settings (e.g., rural areas). Specifically, to advance these efforts:

- The Centers for Disease Control and Prevention and the Administration for Community Living should incorporate REACH II and its adaptations into their efforts to support evidence-based dementia programs at state and local public health departments in concert with community organizations.
- The Centers for Medicare & Medicaid Services should explore the value of REACH II and its adaptations offered as a benefit through Medicare Advantage programs and alternative payment models and for fee-for-service beneficiaries to build the infrastructure, train the workforce, and redesign the workflows that would facilitate the adoption, monitoring, and evaluation of these programs.
- State Medicaid programs serving persons living with dementia and dual-eligible beneficiaries should encourage participating health systems, systems that provide long-term services and supports, and managed care organizations to provide REACH II and its adaptations for care partners and caregivers. This care could be included in a dementia-focused quality metric.
- The National Institute on Aging, HHS's Office of the Assistant Secretary for Planning and Evaluation, the Agency for Healthcare Research and Quality, and the Administration for Community Living should support research and stakeholder engagement focused on REACH II and its adaptations to aid in scaling and sustaining the model; identifying monitoring and evaluation standards; developing monitoring and evaluation plans; and sharing information about key findings, lessons learned, and promising practices.
- The U.S. Department of Veterans Affairs should participate in monitoring, quality improvement, and information-sharing initiatives to enable other entities to learn from its implementation of this intervention.
- Health care systems should support infrastructure that would facilitate the collaboration of providers of primary care, mental health and other specialty care, and long-term services and supports within the health care system and with local home-based community services and supports agencies in implementing REACH II and its adaptations to improve the well-being of persons living with dementia and their care partners and caregivers.

Recommendation 3: Use strong, pragmatic, and informative methodologies.

When requesting applications and identifying funding priorities for research on care interventions for persons living with dementia and their care partners and caregivers, the National Institute on Aging and other interested organizations should prioritize strong, pragmatic, and informative methodologies that take account of this complex domain, including studies that:

- ensure a balanced portfolio of short- and longer-term studies with sufficient sample size;
- use a harmonized core of outcomes and a taxonomy of interventions to enable pooling of study findings;
- focus on outcomes of greatest priority to persons living with dementia and their care partners and caregivers, including intended and unintended benefits and harms, across the continuum of early through late-stage dementia;
- include qualitative methods in studies that have quantitative outcomes;
- use observational study methods to complement randomized trials; and
- commit to comprehensive study reporting to enable improving and better understanding fidelity, studying context effects, and learning from negative results and unsuccessful methodological approaches.

Recommendation 4: Prioritize inclusive research.

When funding research on care interventions for persons living with dementia and their care partners and caregivers, the National Institutes of Health (NIH) and other interested organizations should prioritize research that promotes equity, diversity, and inclusion across the full range of populations and communities affected by dementia through studies that:

- are conducted by broadly inclusive research teams;
- include racially, ethnically, culturally, linguistically, sexually, and socioeconomically diverse participants by requiring adherence to the NIH Revitalization Act of 1993 and assess disparities in access and outcomes; and
- use study designs that support inclusivity.

Recommendation 5: Assess real-world effectiveness.

When funding research on care interventions for persons living with dementia, care partners, and caregivers, the National Institutes of Health, the Agency for Healthcare Research and Quality, the Centers for Medicare & Medicaid Services, the Administration for Community Living, and other interested organizations should support research capable of providing the evidence that will ultimately be needed to make inclusive decisions and implement interventions in the real world, including studies that, to the extent possible:

- improve the assessment of individual-level interventions by leveraging complementary study methodologies;
- expand the focus on community- and policy-level interventions using a broad set of research methodologies; and
- address key factors (e.g., space, human resources, work redesign, and adaptations) that need to be taken into account to assess the real-world effectiveness of these interventions.

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