



October 21, 2022

Chandra Keller
National Institute on Aging
Division of Behavioral and Social Research

RE: Invitation for Input on the 2023 National Research Summit on Care, Services, and Supports for Persons Living with Dementia and their Caregivers/Care Partners (NOT-AG-22-028)

Dear Ms. Keller,

The American Geriatrics Society (AGS) is pleased to respond to the National Institute on Aging's (NIA's) Request for Information (RFI): Invitation for Input on the 2023 National Research Summit on Care, Services, and Supports for Persons Living with Dementia and their Caregivers/Care Partners (NOT-AG-22-028)

The AGS is a nationwide not-for-profit society comprised of more than 6,000 geriatrics healthcare professionals, including basic and clinical researchers specializing in aging. The AGS provides leadership to healthcare professionals, policy makers, and the public by implementing and advocating for programs in patient care, research, professional and public education, and public policy. Our vision for the future involves a world where we are all able to contribute to our communities and maintain our health, safety, and independence as we age because we have access to high-quality, person-centered care informed by geriatrics principles.

We very much appreciate the NIA's efforts to seek input on topics of consideration from interested stakeholders for support for persons living with Dementia and their Caregivers.

AGS specific recommendations on requested topics for the 2023 National Research Summit are below. We believe that each topic area needs to address the following overarching considerations for research going forward so that consideration of these issues is embedded in how we think about the research that has been done to date and what research is needed in a particular topic area.

- Social determinants of health; and
- State of the research on minoritized populations.

We have also included comments on the last topic but would strongly recommend that attention to these areas be infused into the entire conference and not treated as stand alone.

Dementia care models, coordination of care, transitions across a care continuum

- **What attention has been paid to social determinants of health and diversity (age, race, ethnicity, gender) within the data that is used to make clinical recommendations?** Are additional studies of interventions needed that are focused on minoritized communities and/or

on people living in poverty? Are federally qualified health centers and public hospitals adequately resourced to offer dementia care models, care coordination, care transitions, and other interventions that have been shown to support people living with dementia (PLWD)?

- **Palliative approaches to support PLWD** who do not meet current hospice criteria. What is known about supporting PLWD who are residents of senior living, assisted living, nursing homes, or at home with palliative care? What are the main research questions that remain to be answered given that we know that transferring a person living with dementia to these settings is often inconsistent with patient-centered goals? How do we move what we know from research on **non-pharmacological approaches to challenging behaviors** from the research setting into clinical practice.
- **Prescribing and deprescribing in PLWD** - What do we know and what additional research is needed?
- **Health Systems** – What is the role of the healthcare system in managing PLWD, particularly those with multiple chronic conditions (MCC)? What research is needed so that we are more holistically supporting PLWD throughout a health system and ensuring that care is not fragmented?
- **Primary Care** - How can we strengthen primary care practices so that they have the knowledge and skills to manage PLWD in a way that is person-centered? How can we strengthen the role of family and other caregivers so that their voices are heard, and they also are supported through their caregiving journey?

Interventions to support dementia care partners and caregivers, including interventions tailored to address differences in caregiving needs, supports and sources of resilience that may exist across various cultures

- **What attention has been paid to social determinants of health and diversity (age, race, ethnicity, gender) within the data that is used to make clinical recommendations?** What additional research is needed to support older adults who live in public housing, intergenerational families, and people from different cultural backgrounds? As people age, how does ageism intersect with other identifies that have an impact on the healthcare a patient receives? With increasing recognition of the importance and likely causal contributions of many behavioral and other health-related social risk factors to the development of AD/ADRD in later life, we need to understand from a life course perspective when the vulnerability periods are in the aging trajectory and what interventions may be effective for AD/ADRD prevention and when (many of these are likely to be public health, health policy and community org/healthcare partnered interventions).
- **Home and Community-based Care:**
 - Right Care, Right Time, Right Place: What do we know about cost of unnecessary emergency department care and hospital admissions because of the fragmented nature of home and community-based services? What would a system of community-based care look like if it was organized around the concept of person-centered care? Do we understand how to organize the workforce and other services (e.g., respite care) so that PLWD and their caregivers have access to care that meets their needs and that is flexible as those needs change?
 - Workforce: What do is currently known and what questions need to be answered about our community-based workforce? Can we enhance the roles and build career ladders for community health workers so they can serve as educators and liaisons between PLWD/care partners and the health care system? Are there roles that have been shown to be successful -- where more research is needed before they are rolled out more

broadly (e.g., RN navigators to assist with care transitions and emergency department visit prevention)? What additional research is needed so that we are supporting direct care workers across settings to thrive in their chosen career path, including research on what helps this workforce to be resilient.

Home based primary care for PLWD: An overview of what we know about the efficacy of home-based primary care. What can we do to better support this workforce? Is additional research needed on the incentives that would increase the number of people who are going into primary care? The impact of detection and diagnosis on individuals and care partners, as well as social, economic, and structural barriers to, and facilitators of, detection and diagnosis and ethics and equity issues

- **What attention has been paid to social determinants of health and diversity (age, race, ethnicity, gender) within the data that is used to make clinical recommendations?** Do we have sufficient understanding of how families living below the poverty line can integrate healthy lifestyles into their routines (e.g., how do we address food deserts, not having sufficient money to buy healthier foods, etc.)?
- **Lifestyle Interventions to Prevent Dementia:**
 - What is known about lifestyle choices across the lifespan (by this we mean including children) that might prevent dementia? Are there promising lines of inquiry that would benefit from increased funding so that they could be rolled out on a broader scale?
 - Researchers from the Blue Zones claim 90% of dementia could be prevented by a lifetime of healthy diet (and of note, older adults in the Blue Zones are almost completely free of dementia). What additional research is needed to roll out the blue zone findings as an approach that could benefit older adults globally?
 - **Intergenerational Interventions:** Are there Intergenerational lifestyle interventions that show promise for preventing or delaying dementia? E.g., programs that bring grandparents and grandchildren together for learning and other activities? Have we studied how these programs are benefiting children?
 - **Elder Abuse/Mistreatment:** Do we have sufficient numbers of people from diverse economic and cultural backgrounds in studies of elder abuse and mistreatment to inform recommended interventions? Are additional studies needed that are focused specifically on strategies that support families living at or below the poverty line?

Disparities and inequities in healthcare access, utilization, and quality for PLWD

- **What is our understanding of the unmet needs of PLWD who are economically disadvantaged or from different racial/ethnic backgrounds, SES, LGBTQ+?** How does geography (rural, urban, suburban) play into decision-making about where someone lives? Have studies considered, accessibility and affordability for translation into practice? Do we have an understanding of how level of education, type of wage structure (e.g., hourly wage worker vs. salaried employee) plays into a family's capacity to take on caregiving for PLWD?
- **Do we have sufficient understanding of how existing biases and systemic factors fuel disparities that we see in accessing high quality care for PLWD?**
- **Do we have the metrics that will allow us to understand the improvements that we are testing will be accessible to every person living with dementia and not just those with higher socio-economic status?**

- **Is there sufficient research on factors associated with resilience of caregivers and direct care workers** (e.g., education/training, wages, benefits, satisfaction, treatment, empowerment, career pathways, etc.)? The turnover measure that is now on Care Compare will start to hold nursing homes, for example, more accountable to the environments that they are creating that lends themselves to the retention of the workforce and are reflective of a good place to work. More research is needed to understand the implications of environment of the workforce.

Thank you for the opportunity to submit these comments. We would be pleased to answer any questions you may have. Please contact Erin Obrusniak, eobrusniak@americangeriatrics.org.