



Diversity Recommendations

Cross-Cutting Theme Paper

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Additional information can be found at the Summit website (<https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>) 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

Recommendations for the Cross-cutting Theme of Diversity
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Definition: Diversity is broadly defined to include race and ethnicity as well as gender, SES, LGBTQ populations and rural versus urban.

Methodology

1. **Services and interventions research needs to include sufficient numbers of diverse and underrepresented populations to allow for meaningful cross-group analysis.** While the evidence base for caregiver interventions is good for caregivers, prior studies have largely involved white non-Hispanic caregivers and knowledge about effectiveness is much sparser for diverse subgroups. Recruitment of diverse populations for research can be enhanced in a variety of ways that are consistent with community participatory research including:
 - a. begin intervention development and implementation by engaging communities of interest and building upon local resources, values and dementia-related meanings
 - b. prioritize the recruitment and training of research investigators and staff reflecting the ethnic and cultural diversity of the cohorts being studied
 - c. include key informants from communities of interest as part of the research team (e.g., as individual team members, community advisory boards)
 - d. consider innovative marketing and technology-based strategies to activate and engage participants.
2. **Interventions should incorporate measurement of key factors (e.g., environmental, sociocultural, behavioral and biological) that may be particularly salient to caregivers from diverse and under-represented backgrounds.** This will advance our understanding of intervention mechanisms and processes (e.g. moderators, mediators). Choice of variables can be guided by existing frameworks specifying disparity-relevant factors at multiple levels across the life-course such as the NIH Disparities Framework (Hill et al, 2015) or social determinants frameworks.
3. **Research studies need to include valid measures of race and ethnicity that go beyond broad categories (e.g., Latino) to specify specific ethnic subgroups (e.g., Puerto Rican, Dominican, Mexican-American etc.).**

Scientific areas

4. **Research is needed to identify gaps and disparities in quality of care for caregivers within healthcare systems and long-term services and supports.** This data will help identify disparities in the quality of care and areas where interventions may need additional adaptations or more substantial modifications. This data could be included in the evaluation of demonstration projects to implement medical and community-based models of care.
5. **Longitudinal population-based data is needed for diverse populations.** One possible approach to generate this data is to for existing longitudinal studies (e.g., NHATS/NSOC and HRS) to oversample for diverse subgroups.
6. **A multi-site effectiveness trial testing evidence-based interventions in diverse populations and conducted in routine care settings.** If organized through a coordinating center, this trial could create a consortium to generate valuable knowledge on engaging and adapting interventions for diverse populations.

Post-summit activity

7. **A post-summit conference bringing together experts in diversity is needed to accelerate progress in caregiving care and services research for diverse populations.** The goal of this conference would be to develop recommendations on the best approach for engaging culturally diverse groups in research, the most effective strategies for adapting and implementing interventions in “real world settings,” and the priority areas to advance the field. This conference could also be used to make recommendations for the design of the multi-site effectiveness trial (see Recommendation 6 above).