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January 5, 2016

Joe V. Selby, MD, MPH Executive Director Patient-Centered Outcomes Research Institute 1828 L Street, NW, Suite 900 Washington, DC 20036

Dear Dr. Selby,

The <u>Alliance for Aging Research</u> is the leading non-profit organization dedicated to accelerating the pace of scientific discoveries and their application to improve the experience of aging and health. We appreciate the opportunity to provide suggested research topics to the Patient-Centered Outcomes Research Institute (PCORI) aimed at improving outcomes for people with Alzheimer's disease. This disease currently affects as many as 5 million Americans and that number is expected to almost triple by 2050.

According to a recent <u>report</u> by the Alzheimer's Association, the U.S. spends one out of every five Medicare dollars on people with Alzheimer's disease and other dementias. By the middle of this century, that will increase to one out of every three Medicare dollars. For people with Alzheimer's disease and other dementias, Medicare spending is three times higher than spending on those without dementia. Medicaid payments are 19 times higher for those individuals with Alzheimer's disease or other dementias. The elderly is a subpopulation that PCORI is statutorily mandated to focus on in its research and we support your move to fund additional Alzheimer's-specific research projects in order to have the greatest impact on this disease, which fast becoming one of the most prevalent diseases afflicting older adults.

In the absence of a treatment to prevent or modify the course of Alzheimer's disease, our suggested topics to PCORI cover non-pharmacologic interventions and care management options. We would encourage you to consider the following areas for prioritization:

- Impact of non-pharmacologic interventions for Alzheimer's disease on patient outcomes, caregiver burden and rates of institutionalization;
- Evaluation of screening methodologies, for relative ease/uptake and associated optimization across provider groups and settings of care;
- Assessment of how Alzheimer's disease diagnosis and treatment affects management of comorbidities:



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- Frequency of emergency room visits for Alzheimer's disease patients and identification of best practices for potential mitigation;
- Comparisons of currently available tools used to assess cognition to identify which is most effective for specific populations; and
- Impact of knowing positive ApoE genotype status on patient, caregiver, and provider behaviors/outcomes as compared to ApoE negative status.

While we know there are many other worthy topics to consider in this space, we believe that patient-centered outcomes research in these key areas is critical for reducing the burden of Alzheimer's disease on individuals with the disease, their families and our country. Thank you for considering our views. If you any questions, please contact us at (202) 293-2856 or by email at cbens@agingresearch.org or speechin@aingresearch.org.

Sincerely,

Susan Peschin, MHS

President and CEO

Cynthia Bens

Vice President, Public Policy