



March 13, 2012

Joseph Selby, MD
Executive Director
Patient-Centered Outcomes Research Institute
Public Comments
1701 Pennsylvania Ave. NW
Suite 300
Washington, DC 20006

Dear Dr. Selby:

AARP appreciates the opportunity to offer comments on the Draft National Priorities for Research and the Research Agenda recently issued by the Patient-Centered Outcomes Research Institute (PCORI). We support the need for independent and credible comparative effectiveness research (CER) to inform patient and clinical decisions through a synthesis of existing evidence and the production of new data.

AARP supports CER to inform better policy and personal decisions regarding treatment, prevention, and diagnosis; system improvements, including workforce training and deployment; patient self-management, shared decision making, and decision quality; communication and dissemination of CER findings in ways that are useful to multiple end-users, including patients. As an overarching theme, it is important to learn how different treatments, interventions, medications, and delivery approaches affect different population groups, especially those that experience disparate health care results. Finally, we support research that focuses on accelerating research findings by means of innovative methodologies that derive data from clinical workflow, or generated or reported by patients themselves.

We commend PCORI for its consistent emphasis on research that can inform and guide how to enable and support health care delivery that is patient-centered and focused on patient needs. We especially appreciate PCORI's efforts to ensure an infrastructure that incorporates consumer perspectives and involves them in all aspects of the research process: setting priorities, designing research projects, conducting the research, and disseminating the findings.

The proposed priorities for research implicitly acknowledge the large gaps in knowledge that impede efforts to improve health care quality and efficiency. The breadth of the proposed agenda identifies the challenges that lie ahead and illuminates the critical need to extend the knowledge base to improve health care and health care service delivery.

However, AARP believes the initial set of research should demonstrate PCORI's great potential to conduct and disseminate impactful, highly relevant research. Producing information that informs patients and clinicians in areas where current knowledge is lacking or equivocal would reaffirm PCORI's *raison d'être*. Priority should be given to conditions where there is high cost and high volume; instances where gaps in knowledge are known to exist; conditions where there is a demonstrated significant disease burden; and conditions where there exists high variation in care delivery and outcomes, particularly for older persons, women, and minority populations. Integral to all of this research must be an exploration and analysis of the effects on minority populations. Every relevant research project should address disparities of care as an overarching, crossing-cutting area for study.

In addition, we encourage PCORI to give translational research priority as well to maximize the investment already made in basic research and laboratory science by identifying strategies that can hasten implementation of these findings to prevent or treat diseases.

PCORI's agenda can complement and supplement other efforts, always with a consumer focus, and we strongly urge PCORI to do so to the extent possible as a means of avoiding duplicative effort and maximizing resources by targeting priorities that have already been identified through consensus and other multi-stakeholder efforts. As PCORI refines its research agenda, AARP encourages coordination with other initiatives, including the Department of Health and Human Service's national priorities and strategy; the quality measurement enterprise, particularly the work of the National Quality Forum; the Center for Medicare and Medicaid Innovation, and the initiatives of the Office of National Coordinator with respect to meaningful use of health information technology.

Finally, we encourage PCORI to remain flexible in order to respond to other research topics as these need emerge.

In conclusion, we reemphasize areas of great importance to AARP members and the 50+ population as deserving priority status, including the urgent need for research on disparities, caring for people with co-morbidities, (including the critical need to improve care coordination), and ways to produce high quality care more efficiently and cost effectively. In addition, the work on dissemination needs to take a broad look to be sure we reach *all* potential users — especially patients and their caregivers, members of minority groups, and clinicians in small practices — when such users are most likely to make use of the research results — at the point of care.

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Thank you for the opportunity to provide comments on the development of comparative effectiveness research priorities. We greatly appreciate that PCORI has committed to ensuring that as the specific research projects are implemented, consumers will be directly involved in the design of the investigations and the development of the research questions to be addressed. We are prepared to work with you to advance CER and PCORI's research priorities and agenda. If you have any questions about our comments or suggestions, please do not hesitate to contact Leah Cohen Hirsch of our Government Affairs Health team at 202-434-3770.

Sincerely,

A handwritten signature in black ink, appearing to read "David Certner", with a long horizontal flourish extending to the right.

David Certner
Legislative Counsel and Legislative Policy Director
Government Affairs