

To: Patient-Centered Outcomes Research Institute  
Public Comments  
1701 Pennsylvania Ave. NW,  
Suite 300  
Washington, DC 20006

From: Susan Lin, Research Director

Date: February 29, 2012

Subject: Public Comment on the Patient-Centered Outcomes Research Institute’s (PCORI) National Priorities for Research and Research Agenda

The **American Occupational Therapy Association (AOTA)**, representing the interests of over 140,000 occupational therapy practitioners nationwide, appreciates this opportunity to comment on the Patient-Centered Outcomes Research Institute’s (PCORI) National Priorities for Research and Research Agenda.

We are pleased to see that PCORI is thoughtfully addressing priorities for patient-centered comparative clinical effectiveness research to improve the health care of our nation.

[For remainder of document, **Bold** indicates PCORI’s questions]

**Please indicate what percentage of the PCORI comparative effectiveness research budget you think should be invested in each of the five Priorities and why?**

Assessment of Options for Prevention, Diagnosis, and Treatment	Improving Healthcare Systems	Communications and Dissemination Research	Addressing Disparities	Accelerating Patient-Centered Outcomes Research and Methodological Research
35	20	10	10	25

**Total should equal 100%**

**Accelerating Patient-Centered Outcomes Research and Methodological Research**

**Please indicate the reason for your suggested budget.**

AOTA lauds the plans to accelerate patient-centered outcomes and methodological research and we recommend a slight increase (i.e., additional 5%) in funding towards this priority because of the following reasons:

- (a) Involving patients and other stakeholders in rigorous research can require additional time and resources
- (b) Building research networks and accelerating infrastructure will require funding and support
- (c) Expanding the PCOR workforce will also require time to sufficiently educate and train these professionals

**The National Priorities do not currently focus on diseases. Rather, they focus on types of research issues that address major challenges in health care delivery. In the future, portions of the Research Agenda may focus on specific conditions. If future versions of the Research Agenda focus on specific conditions and diseases, how should PCORI choose which ones to target?**

**Comments**

Perhaps there is a way to prioritize conditions based on prevalence, health care or societal cost, and evidence gaps for each condition. By evidence gaps, we mean that a condition that is progressive, limiting the daily function of the patient, with no evidence-based cure or treatments, should receive a higher priority over a condition that has several treatments currently used in

**How might PCORI engage in emerging public health issues?**

PCORI could work with other agencies (e.g., CDC, IOM, NIH) to conduct surveillance and identify emerging public health issues and partner with professional organizations/associations to disseminate opportunities for research or research findings. For example, within occupational therapy, we are concerned about mild to moderate traumatic brain injury in athletes and wounded warriors, as well as the increasing prevalence of Alzheimer's disease, currently 13% in adults aged 65 or older.

Reference:

Hebert, L.E., Scherr, P.A., Bienias, J.L., Bennett, D.A., Evans, D.A. (2003). Alzheimer's disease in the U.S. population: Prevalence estimates using the 2000 Census. *Archives of Neurology*, 60(8), 1119-1122.

**In the Affordable Care Act, PCORI is tasked with addressing rare and understudied diseases. Please suggest ways PCORI could address conditions that are rare and currently understudied?**

- Provide additional research funding to organizations and researchers working on those conditions
- Target a specific set of conditions (please tell PCORI what criteria you think should be used to select specific conditions in the comment box below)
- Identify top needs based on PCORI's mission

- **Create research partnerships with organizations currently working on these conditions**
- **Support electronic data sources where patients can securely volunteer their health data and the appropriate researchers can use it to answer PCORI research questions on rare conditions**

**(check all that apply)**

**Other Comments**

PCORI could identify a list of conditions that are rare and prioritize them based upon which conditions have no cure or effective treatment, and which are progressive and likely to lead to disability. Weights could be assigned to each of these variables to help prioritize the conditions. The role of health care professionals (e.g., occupational therapy) should be described for individuals with these conditions because we can strategize with patients and their families to improve health-related quality of life, adapt environment or provide assistive technology to enable functional independence, provide palliative care, teach self-management strategies, and facilitate performance in everyday activities and participation in society.

**The five priorities are: Assessment of Options for Prevention, Diagnosis, and Treatment; Improving Health Care Systems; Communication and Dissemination Research; Addressing Disparities; and Accelerating Patient-Centered Outcomes Research and Methodological Research. What do you suggest might be important Research Agenda topics that should be included in any of the five Priorities?**

AOTA appreciates PCORI’s emphasis on the Comparisons of Prevention, Diagnosis, and Treatment Options. We strongly agree with the need to examine the multiple factors affecting patient outcomes. In medicine, some consider patient outcomes in terms of absence of disease, mortality, or biological measures (e.g., lab results). In occupational therapy, we consider patients’ outcomes in terms of patients’ ability to perform daily activities and participate in the roles in which they ascribe meaning. Being able to return to one’s meaningful roles and participate in one’s community is inextricably linked to quality of life. Our concern about defining patient outcome stems in part from the observation that “function is in the eye of the beholder”. For example, there is literature referring to function but upon closer examination, the researchers have operationally defined function as bed mobility or a Functional Independence Measure score (which really measures burden of care rather than performance per se). Therefore, we respectfully request that PCORI consider patient outcome in the broadest sense because across the lifespan and across diagnoses, performance of meaningful activities and participation define us as individuals and contribute to the health of our society.

**10. Please provide any other questions or comments on the Research Agenda.**

We agree with the five categories of the first research agenda and we hope that PCORI will fund effectiveness studies and implementation studies. We concur with the statement, “Ultimately, decisions about funding will depend on the quality of the applications – with special attention to the likelihood that the **research may lead to improvement in patient outcomes**, as determined by alignment with PCORI criteria [emphasis added] (see p. 12). We suggest using this criterion, “the likelihood that the research may lead to improvement in patient outcomes”, to evaluate applications for funding because ultimately, improving patient outcomes is our goal.

**11. Please provide any additional comments not mentioned in your previous responses to the specific questions about the National Priorities for Research and Research Agenda.**

Regarding the category, Improving Healthcare Systems, in the Research Agenda, AOTA applauds the inclusion of allied health professions in comparing the effectiveness on patient outcomes (section 2. B). Occupational therapists could play an important role in care coordination, safety and independent functioning at home/residence, self-management of chronic conditions, and the evaluation of needs for adaptive equipment or assistive technology. Our goal is to maximize the functioning of patients and facilitate their performance of meaningful activities and participation in their communities.

The American Occupational Therapy Association thanks PCORI for providing this opportunity to comment and we look forward to collaborative opportunities to improve patient-centered outcomes.