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March 5, 2012

Patient-Centered Outcomes Research Institute (PCORI)
Public Comments

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Washington, DC 20006

Email: info@pcori.org

Written comments also submitted to website under:

“Provide General Feedback” form on the bottom of web page at:
<http://www.pcori.org/provide-input/>

Subject: PCORI Public Comment – Draft National Priorities for Research and Research Agenda Version 1

To Whom It May Concern,

The American Academy of Neurology (AAN) represents 25,000 neurologists and neuroscience professionals. Our mission is to promote the highest quality patient-centered neurologic care. We are pleased to provide comment on the PCORI Draft National Priorities for Research, and Research Agenda.

By providing the following comments, the AAN as a medical specialty society demonstrates the commitment to and their role in advancing comparative effectiveness research (CER). We strive to create a “learning health care system” approach (refer to enclosure) through alignment of evidence-based medicine (EBM) principles in our clinical practice guidelines, quality measurement sets, and physician-patient communication tools. The approach is best demonstrated through our efforts under development to:

- Educate members about how to talk to their patients about evidence-based medicine, emphasizing the importance of fully disclosing risks and benefits discovered in the research, and describing all viable treatment options.
- Educate members about how to elicit patients’ concerns, preferences, and values.
- Engage with patient advocates to promote educating their constituents about the importance and validity of CER and how it can help advance more personalized care.
- Promote shared decision-making, including the use of decision aids that incorporate CER findings.

Given the AAN’s commitment and ongoing enhancements to their existing enduring materials, we share the following comments:

National PCORI Priorities:

- The national PCORI priorities are uncontroversial.
- The “communication and dissemination” goal is most concordant with the current efforts of the American Academy of Neurology and has the AAN’s support as a highest priority. This is an area where not only is the gap large,

but there are few other federal dollars dedicated to address this priority. The private sector is incentivized to address “communication and dissemination” when there is financial gain. This is at variance with the “comparative effectiveness” motivation, which is expected to lead to utilization of the least expensive resources needed to attain effectiveness. PCORI needs to focus on developing usable end products for dissemination and application by clinicians and patients.

- The other goals, while important, are secondary.
- Funding of PCORI priorities needs to avoid duplication of existing efforts in both research and infrastructure. For example, where adequate alternative funding sources are available, such as for developing options for prevention, diagnosis, and treatment, PCORI should support the utilization of existing sources and focus its unique funds on its other priorities.
- PCORI needs to have an ongoing evaluation plan to measure how it is meeting its goals.

National PCORI Research Agenda:

- The national PCORI research agenda is uncontroversial. The following is a list of agenda topics that the AAN proposes to be included in the five *Priorities*:
 - Quality of care in smaller, rural hospitals versus tertiary care large hospitals from the perspective of stakeholders (patients, providers, insurers).
 - Value of high-priced interventions in health care from the perspective of stakeholders, especially patients and caregivers.
 - Definition of outcomes and determination of how selected outcomes apply to specific diseases, patient populations, provider type, and structure.
 - Emphasis on improved communication between health care providers and patients/caregivers.
 - Address payment and reimbursement structures and strategies to ensure that physicians and other healthcare providers are not dis-incentivized to participate in patient- and outcome-oriented practice. PCORI must ensure that clinicians are not alienated or ignored and that patient-physician communication research agendas support this fundamental concept.

We thank PCORI for consideration of our comments. If you have any questions concerning the contents of this letter, please contact Rebecca Penfold Murray at 651-695-2735 or rpenfoldmurray@aan.com.

Sincerely,



Bruce Sigsbee, MD, FAAN
President, American Academy of Neurology

Encl: Learning Health Care System

Learning Healthcare System Approach to Advancing Comparative Effectiveness Research

Background:

The following ten major steps provide guidance to specialty societies and patient advocates to create a “learning health care system” and promote the use of CER. These emerged from a meeting sponsored by AARP, the ABIM Foundation, and the Council of Medical Specialty Societies in March 2011, which brought together leaders from specialty societies, patient advocacy groups, business, insurers, and the federal government. They produced a formal recommendation document in May 9, 2011—“ABIM-F CER Recommendations 05-09-11.”

President Bruce Sigsbee, MD, FAAN approved the AAN endorsing the recommendations as approved by the Practice Committee in June 2011. The recommendations were endorsed by the Council of Medical Specialty Societies (CMSS) Board and by a workgroup with representatives from CMSS, ABIM-F and AARP. The CMSS organizations which participated include ACR, ACOG, ACS, AAFP, ACC, AUA, ACP, and STS.

Background:

Role of Specialty Societies in Advancing CER

Research

1. Ensure patients and clinicians play active roles in designing CER studies and identifying the research questions to be studied.
2. Ensure that the reports produced by the researchers undertaking CER studies are written to maximize their value for physicians and patients.
3. Specialty societies and patient advocates should support complete transparency in CER.

Access/Dissemination

4. Incorporate CER findings as quickly as possible into practice guidelines, patient guides, and other educational and communication tools.
5. Advocate for decision support tools that incorporate guidelines reflecting CER findings.

Physician-Patient Communication

6. Educate members about how to talk to their patients about evidence-based medicine, emphasizing the importance of fully disclosing risks and benefits discovered in the research, and describing all viable treatment options. Physician communication should also elicit patients’ concerns, preferences, and values. Patient advocates should educate their constituents about the importance and validity of CER, describing how it can help advance more personalized care.
7. Promote shared decision-making, including the use of decision aids that incorporate CER findings.

Measurement

8. Encourage measure developers to develop measures that are based on proven evidence.
9. Build and expand registries, they should consult with PCORI and others to ensure that data that could advance CER are captured.

Promoting CER

10. Encourage constituents to communicate the benefits of CER within the medical and patient communities and among the public.