



March 15, 2012

Patient-Centered Outcomes Research Institute (PCORI)  
1701 Pennsylvania Ave. NW, Suite 300  
Washington, DC 20006

Re: Comments on Version 1 Draft National Priorities and Research Agenda

Dear Patient-Centered Outcomes Research Institute:

On behalf of AMIA (the American Medical Informatics Association) and its Nursing Informatics Working Group (NIWG), we are pleased to submit these comments in response to your request for comments on the Version 1 Draft National Priorities and Research Agenda. AMIA's NIWG promotes the advancement of nursing informatics within the larger interdisciplinary context of health informatics. The Working Group and its members pursue this goal in many areas including professional practice, education, research, governmental and other service, professional organizations, and industry.

AMIA thanks the Patient-Centered Outcomes Research Institute (PCORI) for providing an open comment period to solicit input on the PCORI National Priorities and Research Agenda. While you note that the scope of your proposed research agenda was designed to be intentionally broad, we look forward to seeing more details and greater specificity about your proposed strategy and focus. We believe that providing additional specificity will produce a more useful research agenda and thus enable researchers to focus their responses to your requests for proposals. We are pleased to see a number of items included in the draft such as: the emphasis on prevention as well as the focus on safety and effectiveness of alternative preventive, diagnostic and treatment options spanning different populations who may respond in distinct ways. We especially appreciate the prioritization of research related to shared decision-making between patients and providers.

We applaud your intentions to help assure that PCORI's efforts not duplicate what is already underway or contemplated by other organizations such as the Agency for Health Care Research and Quality (AHRQ), the Centers for Medicare and Medicaid Services (CMS), the National Institutes of Health (NIH); the Institutes of Medicine (IOM); philanthropies<sup>1</sup> and other private

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<sup>1</sup> Commonwealth Fund. Rising to the Challenge: Results from a Scorecard on Local Health Performance, 2012  
<http://www.commonwealthfund.org/Publications/Fund-Reports/2012/Mar/Local-Scorecard.aspx> .

sector organizations. However, it is not clear how such potential duplication will be monitored and ideally avoided.

The document notes that “PCORI intends to invest in efforts to maintain active engagement with patients and all other stakeholder groups over time.” We urge PCORI to provide further clarification on engagement with patient and consumer groups and stakeholders as well as to provide additional information on how PCORI will coordinate such engagement with other Federal agencies such as AHRQ and the Department of Health and Human Services (DHHS) (page 12). For example it is not clear if or how PCORI’s efforts and topics will relate to those described in Federal reports and initiatives such as: the National Priorities Partnership; National Quality Strategy; National Healthcare Disparities Report; and National Healthcare Quality Report.

### **PCORI’s Proposed National Priorities for Research**

We understand that the five comparative effectiveness research priorities were “developed in light of PCORI’s statutory requirements” and we note PCORI’s statements about not wanting to be too prescriptive or exclusive. However, while the general categories seem reasonable, we suggest that PCORI provide further clarification of the proposed categories, including definitions for terms and terminology and their consistent use. Inclusion of a glossary would be useful. Additionally, it is not clear if or when some of these terms are used interchangeably.

The document would benefit from the inclusion of citations to support some of the broader statements that appear (for example, on page 10, “PCORI’s national priorities can be applied to and used to advance the quality of information for any health condition or disease where evidence is lacking or current decision making is sub-optimal”).

We suggest that PCORI’s five research priorities include attention to improving health literacy among patients, their families and caregivers. We believe that including literacy is important to help propel and facilitate more scientific research in this area and could be included as one of the core components under “Addressing the Disparities.”

Under “Improving Health Systems” (page 10), we read “innovative use of health information technology”. Since the health sector is on the brink of wide-scale implementation of robust health information technology, there is a pressing need to increase and broaden the pool of workers who can help healthcare organizations and practitioners to maximize the effectiveness of their investments in such technology. Strengthening the breadth and depth of the biomedical and health informatics workforce is a critical component of the transformation of the American healthcare system through the deployment and use of HIT and we urge PCORI to consider the health IT and informatics workforce as part of its priorities and funded research.

Ongoing workforce shortages and the lack of an effective deployment of the workforce is a significant present gap. For example, certain professional practices are limited in providing the delivery of care and oversight due to current state/federal regulations and reimbursement models.

This, another needed focus is research to explore options to remove practice barriers that are impeding the necessary healthcare transformation to achieve the goals of the Triple Aim.

Another focus should be an increase in attention to the role of interprofessional team members in reshaping primary care delivery as a cornerstone to health reform. We encourage PCORI to focus efforts on the capture of care team data to support care coordination across multiple and diverse care settings and to engage patients, families and consumers.

We also suggest that PCORI consider focusing attention on person/patient accountability, and support for behavioral change via evidence-based health interventions and empowerment. Practice-based evidence application allows for more person-specific and conditional interventions. There is an ongoing need to include issues related to activities of daily living and population health. We suggest including patient-defined elements to address quality of life questions. Research could explore tools that would help patients identify and support their health and their priorities for health vs. priorities as defined by the healthcare practitioner.

Page 15 asks if medical care reflects wide variation in practice or clinical outcomes. We recommend this be revised to recognize person centered care delivery more explicitly and to do so in the context of the entire interprofessional team. The IOM and others are currently exploring issues related to professional roles<sup>2 3</sup> and team-based care<sup>4</sup>, innovations in health professional education<sup>5</sup>, and interdisciplinary education. Their activities should be considered and leveraged but not duplicated.

### **PCORI's Draft/Proposed Research Agenda**

AMIA is committed to the education and training of informaticians to lead the needed transformation and views this activity as a fundamental component of any effort to enhance the safety and efficacy of health and health care and the health information technology systems used to enable and support care. Biomedical and health informaticians are experts in the use of information that is derived from basic biomedical research (biomedical informatics); they also

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<sup>2</sup>The Future of Nursing: Leading Change, Advancing Health <http://www.iom.edu/Reports/2010/The-Future-of-Nursing-Leading-Change-Advancing-Health.aspx>

<sup>3</sup> Health professionals for a new century: transforming education to strengthen health systems in an interdependent world. Julio Frenk, Lincoln Chen, Zulfiqar A Bhutta, Jordan Cohen, Nigel Crisp, Timothy Evans, Harvey Fineberg, Patricia Garcia, Yang Ke, Patrick Kelley, Barry Kistnasamy, Afaf Meleis, David Naylor, Ariel Pablos-Mendez, Srinath Reddy, Susan Scrimshaw, Jaime Sepulveda, David Serwadda, Huda Zurayk The Lancet 2010; 376: 1923-1958

<sup>4</sup> IOM Best Practices Innovation Collaborative <http://iom.edu/Activities/Quality/VSRT/2012-FEB-28.aspx>

<sup>5</sup> IOM Global Forum on Innovation in Health Professional Education <http://www.iom.edu/Activities/Global/InnovationHealthProfEducation.aspx>

apply their skills to the clinical care of patients (clinical informatics) and help to protect the public through a wide range of public health activities (population and public health informatics).

Informaticians' knowledge base and sensitivities span a wide range of disciplines including biomedical and health sciences, organizational behavior, and cognitive science, as well as computer and communications technology. A key goal of biomedical and health informaticians is to integrate multidisciplinary knowledge in the design, construction, and implementation of systems that can assure safe, timely, efficient, equitable, patient-centered, and effective care for individuals and populations. This includes knowledge and skills relating to monitoring and evaluating HIT, with a commitment to pursue open exchange of information about systems coupled with interventions to correct or mitigate problems as they are identified

AMIA directs PCORI's attention to several reports that have been published from AMIA's Annual Public Policy meetings that relate to several of the topics listed in the draft PCORI research agenda and because they describe several potential research topics.<sup>6 7 8</sup>

Page 9 of the PCORI proposed research agenda highlights that health IT and other technologies have not been elevated as a priority within and across the agencies noted. Thus, we believe that additional efforts are needed to synthesize the results of existing and future studies on health IT in order to capture, compile, and disseminate best practices and guidelines for designing and implementing HIT systems; these should include usability guidelines, as well as proven technical and organizational safeguards.<sup>9</sup>

While one of the specific five priorities is "communication and dissemination research" we suggest that there be a focus on the spread and dissemination of innovation in all PCORI funded

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<sup>6</sup> McGowan JJ, Cusack CM, Bloomrosen M. The future of health IT innovation and informatics: a report from AMIA's 2010 policy meeting. *J Am Med Inform Assoc.* 2011 Oct 28. [Epub ahead of print]

<sup>7</sup> Bloomrosen M, Detmer DE. Informatics, evidence-based care, and research; implications for national policy: a report of an American Medical Informatics Association health policy conference. *J Am Med Inform Assoc.* 2010;17(2):115-23.

<sup>8</sup> Bloomrosen M, Starren J, Lorenzi NM, Ash JS, Patel VL, Shortliffe EH. Anticipating and addressing the unintended consequences of health IT and policy: a report from the AMIA 2009 Health Policy Meeting. *J Am Med Inform Assoc.* 2011;18(1):82-90.

<sup>9</sup> Edward H. Shortliffe, MD, PhD TESTIMONY TO HIT Policy Committee, Adoption/Certification Workgroup Office of the National Coordinator for Health Information Technology Department of Health and Human Services Thursday, February 25, 2010  
[http://healthit.hhs.gov/portal/server.pt?open=512&objID=1473&&PageID=17117&mode=2&in\\_hi\\_userid=11673&cached=true](http://healthit.hhs.gov/portal/server.pt?open=512&objID=1473&&PageID=17117&mode=2&in_hi_userid=11673&cached=true)

research. We believe that the inter-relationship between patient safety and quality of care cannot be understated and warrants a more explicit focus. New and diverse data sources, health technologies and devices for data collection and reporting, treatment support, and information dissemination are emerging and being adopted with increasing regularity.

Other environmental factors, trends and issues impacting clinical data capture and documentation include increasing achievements in personalized medicine, growing pressure for consumer engagement in healthcare decisions, new forms and models of care delivery and payment, adoption of electronic health records (EHRs), personal health records (PHRs) and health information exchange (HIE), and ongoing healthcare workforce shortage and training issues. These factors should be addressed and considered in funded research. The availability and use of genomic data and genetic testing data and its evolving impact on healthcare delivery requirements should be made more explicit. Additionally we suggest the inclusion of post-treatment support to include post acute care support and transition as part of “Assessment of Prevention, Diagnosis, and Treatment Options”.

PCORI should promote additional information dissemination as part of patient-centered outcomes research. Enhanced communication among stakeholders in different sectors and disciplines will strengthen our collective ability to identify and address patient safety and quality of care issues. For example, additional efforts are needed to develop, vet and disseminate widely-accepted methods to identify system design features and organizational attributes that can lead to failure or success of various prevention, diagnosis and treatment options as well as health information technology-enabled options. Research is required to explore options so that organizations will be more willing and able to share information about technical and organizational safeguards to address patient safety and quality of care issues. Additional research is needed to support ongoing identification of patient safety and quality of care issues related to HIT design and implementation efforts and the situations in which they are most likely to occur. Resources should be allocated to develop and implement critical evaluative efforts

Page 12 notes that decisions about funding will be contingent upon the quality of the applications. We suggest that PCORI include specific evaluation criteria in its calls for proposals and funding opportunities to clarify expectations for submissions and to help assure responsive proposals.

We suggest that PCORI consider quantitative measurements and qualitative case studies that might highlight the positive impact associated with new care delivery strategies. There must be a balance between leaving design open vs. expectations to measure qualitative and quantitative aspects.

## **Features of the PCORI Research Agenda (pg 22)**

We appreciate the inclusion of the Appendix (Features of the PCORI Research Agenda). We suggest that the relationship between the enumerated features and the PCORI Criteria (page 6) be clarified. We request that additional details be provided about how the features “will be associated with PCORI research and emphasized in PCORI activities”

## **Concluding Remarks**

AMIA is grateful for the opportunity to submit these comments. Again, we thank PCORI for soliciting public input to help inform the finalization of the PCORI Version 1 Draft National Priorities and Research Agenda. Please contact us at any time for further discussion of the issues we have raised.

Sincerely,



Edward H. Shortliffe, MD, PhD, FACMI  
President and CEO, AMIA



Rosemary Kennedy, RN, MBA, FAAN  
Chair, AMIA Nursing Informatics Working Group

## **About AMIA**

AMIA is an unbiased, authoritative source within the informatics community and the healthcare industry. AMIA and its members are transforming health care through trusted science, education, and practice in biomedical and health informatics. AMIA members – 4,000 informatics professionals from more than 65 countries – belong to a world-class informatics community where they actively share best practices and research for the advancement of the field. Members are subject matter experts dedicated to expanding the role that informaticians play in patient care, public health, teaching, research, administration, and related policy. As the voice of the nation’s top biomedical and health informatics professionals, AMIA plays a leading role in moving basic research findings from bench to bedside, evaluating interventions across communities, assessing the effects of health innovations on public policy, and advancing the field of informatics.