



# National Health Council

1730 M Street NW, Suite 500, Washington, DC 20036-4561 ■ 202-785-3910 ■ www.nationalhealthcouncil.org ■ info@nhcouncil.org

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March 15, 2012

Joe V. Selby, MD, MPH

Patient-Centered Outcomes Research Institute

Public Comments

1701 Pennsylvania Ave. NW

Suite 300

Washington, DC 20006

Re: Draft National Priorities for Research and Research Agenda, Version I

Dear Dr. Selby,

The National Health Council (NHC) appreciates the opportunity to submit comments on the PCORI Draft National Priorities for Research and Research Agenda, issued on January 23, 2012. The NHC shares PCORI's goal to ensure comparative effectiveness research (CER) offers patients, providers, and caregivers the information they need to make important health care decisions. As such, we fully support PCORI's prioritization of research on Improving Health Systems, Communication and Dissemination, and Addressing Disparities. To further PCORI's goal of ensuring the development of research that aids patient decision making, the NHC encourages PCORI to define an explicit role for patients in its processes.

The NHC is the only organization of its kind that brings together all segments of the health care community to provide a unified voice for more than 133 million people with chronic diseases and disabilities and their family caregivers. Made up of more than 100 national health-related organizations and businesses, its core membership includes approximately 50 of the nation's leading patient advocacy groups, which control its governance. Other members include professional societies and membership associations, nonprofit organizations with an interest in health, and major pharmaceutical, medical device, biotechnology, and insurance companies.

## National Priorities

PCORI's five priorities for research are representative of a wide range of health care research needs. To people living with chronic conditions, research on three priority areas – Improving Health Systems, Communication and Dissemination, and Addressing Disparities – are of particular importance.

- *Improving health systems.* People with chronic conditions and those living with disabilities access a complex range of health care services and interact with numerous providers throughout the health care system. More research is

needed on new models of health care delivery that can achieve better coordination of services across the continuum of care. As such, we fully support PCORI's focus on research that would compare these system-level approaches.

- *Communication and dissemination.* The NHC recognizes the formidable challenge of transferring research findings into clinical practice. While the past decade has seen an acceleration in CER investments, very little is understood about how best to disseminate and facilitate the use of those research findings by patients and their providers. Thus, we support PCORI investments in research to investigate strategies for transferring research findings into the real world.
- *Addressing disparities.* Progress toward eliminating health disparities has been unacceptably slow. The NHC supports funding of research that compares approaches to reducing health disparities so that quality health care can be accessed by all individuals.

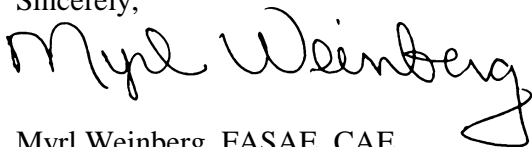
While the precise distribution of funding should be left to PCORI's discretion, we encourage PCORI to revisit its initial funding levels for these priorities, but in particular for 'Communication and Dissemination' research, which according to the draft report is slated to receive only 10% of funding. We believe this level of relative funding is insufficient to achieve PCORI's goals. Identifying new approaches to communication and dissemination is fundamental to attaining PCORI's overarching objective to assist patients and clinicians make informed health care decisions. An ineffective communication and dissemination strategy could render even the highest-quality research meaningless if the information is not appropriately delivered to patients. We urge PCORI to increase the funding allocation for this priority.

### **Patient Engagement**

The NHC appreciates PCORI's efforts to engage the patient community through roundtables and dialogues as well as through outreach conducted by PCORI staff. However, more needs to be done to maximize transparency in PCORI's processes. We believe a key step in improving transparency is by establishing a defined role for patients. Today, opportunities for patient engagement in PCORI's processes are irregular and inconsistent. Formalizing opportunities for patient engagement within PCORI by establishing clear points of engagement would help stimulate high-quality input from patients on their concerns and questions. Knowing how and when to participate with sufficient lead time to prepare and knowing what outcomes to expect from participation would improve process transparency. If PCORI's ultimate aim is to ensure that funded research results in findings that enable patients to make more informed decisions, patients must be effectively integrated in PCORI's work.

The NHC is prepared to collaborate with PCORI to facilitate and promote robust engagement by patients in the conduct of your work. The NHC appreciates the opportunity to share our comments. Please do not hesitate to contact Eric Gascho, our Director of Government Affairs, if you or your staff would like to discuss these issues in greater detail. He is reachable by phone at 202-973-0545 or via e-mail at [egascho@nhcouncil.org](mailto:egascho@nhcouncil.org). You may also reach me on my direct, private line at 202-973-0546 or via e-mail at [mweinberg@nhcouncil.org](mailto:mweinberg@nhcouncil.org).

Sincerely,



Myrl Weinberg, FASAE, CAE  
President