



National Health Council

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Statement of the National Health Council and The National Working Group on Evidence-Based Health Care on Appointments to Patient-Centered Outcomes Research Institute

Washington, DC -- As organizations that are committed to promoting accurate and appropriate evidence-based policies and practices to improve the quality of health care services in the United States, we are disappointed that the appointment today of 19 members to the Board of Governors for the new Patient-Centered Outcomes Research Institute (PCORI) includes only one Board member that directly represents patients.

There is no question that all the members who have been appointed will bring substantial knowledge and professional experience to this critical initiative. However, we believe there needs to be a more significant and substantial representation of patients if we are to ensure that they have a meaningful role and voice in comparative effectiveness research.

The National Health Council and The Working Group on Evidence-Based Health Care strive to empower patients and consumers by involving them in designing and prioritizing research, as well as reviewing evidence and contributing to its translation, dissemination and implementation. We believe it is essential to broaden the participation of the patient in all aspects of comparative effectiveness research if we are to improve the usefulness of evidence for consumers and clinicians. Significant roles for patient advocates are essential to ensuring we effectively evaluate and improve health care services and therapies.

We look forward to close working relationships with the PCORI Board and hope that as openings occur on the PCORI Board, voluntary health organizations will be more represented. This is essential to ensure that patients have a meaningful role and voice in these critical decisions.

The NHC is the only organization of its kind that brings together all segments of the health care community to provide a united voice for the 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 50 of the nation's leading patient advocacy groups which control its governance. Other members include professional and membership associations, nonprofit organizations with an interest in health, and major pharmaceutical, medical device, and biotechnology companies. To learn more, visit www.nationalhealthcouncil.org.

The National Working Group on Evidence-Based Health Care (the Working Group) is a collaboration of patient/consumer organizations, professional societies, providers, researchers, and other interested stakeholders that want to stay abreast of the developments and initiatives in evidence-based healthcare. Since January 2006, the Working Group has sought to educate and engage patient/consumer groups, as well as other stakeholders and to advance the dialogue about meaningful participation by patient/consumer stakeholders in such efforts. For more information about the Working Group, please visit: www.evidencebasedhealthcare.org.

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