



National Health Council

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National Health Council Receives PCORI Award to Advance Patient Involvement in Health Quality Research

Washington, DC (June 13, 2016) – The Patient-Centered Outcomes Research Institute (PCORI) has awarded the National Health Council (NHC) \$246,300 through the PCORI Eugene Washington Engagement Award program to create a patient-specific curriculum on health care quality.

“Stakeholders agree health care quality should be measured and such information should be used by patients to decide among providers and treatments,” said Eleanor Perfetto, NHC Senior Vice President of Strategic Initiatives. “However, patients and the organizations that represent them have not been significantly involved in the development and evaluation of quality measures and performance programs. How can quality measures reflect aspects of care and outcomes important to patients if people with chronic conditions aren’t part of the process?”

NHC, collaborating with the National Quality Forum (www.qualityforum.org) and University of Maryland (www.umd.edu), will create a patient-specific curriculum on health care quality to help patient advocacy organizations and people with chronic diseases and disabilities understand the importance of their engagement in health quality discussions; the terms and definitions of quality measurement research, development, testing, and evaluation; how quality programs are implemented and their impact on patients; and how patients can be meaningful participants in quality engagement opportunities.

“The grant is integral to helping us educate patients about their essential role in the creation of health care quality measures,” said Perfetto. “The result of this initiative will aid researchers in measure development so that they can find patient partners to collaborate with and craft measures relevant to the outcomes considered important to people with chronic conditions. Through improved communications and greater patient engagement, researchers, payers, and policymakers will be able to refine quality-related efforts in a way that enhances our health care system.”

The project is part of a portfolio approved for PCORI funding to help develop a skilled community of patients and other stakeholders from across the entire healthcare enterprise and to involve them meaningfully in every aspect of PCORI’s work. Project funding runs through December 2017.

The National Health Council (NHC) is the only organization that brings together all segments of the health 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

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health-related organizations and businesses, the NHC's core membership includes the nation's leading patient advocacy organizations, which control its governance and policy-making process. Other members include professional and membership associations, nonprofit organizations with an interest in health, and representatives from the pharmaceutical, generic drug, health insurance, medical device, and biotechnology industries.

PCORI is an independent, non-profit organization authorized by Congress in 2010 to fund comparative effectiveness research that will provide patients, their caregivers, and clinicians with the evidence needed to make better-informed health and health care decisions. PCORI is committed to seeking input from a broad range of stakeholders to guide its work.

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