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August 27, 2021

Nakela L. Cook, MD, MPH

Executive Director

Patient-Centered Outcomes Research Institute (PCORI)

1828 L Street NW, Suite 900

Washington, DC 20036

Dear Dr. Cook:

On behalf of the National Health Council (NHC), I am pleased to offer the following comments on the proposed national priorities for health. We appreciate our long partnership with the Patient-Centered Outcomes Research Institute (PCORI) and the opportunity to provide input into shaping these priorities.

Created by and for patient organizations 100 years ago, the NHC brings diverse organizations together to forge consensus and drive patient-centered health policy. We promote increased access to affordable, high-value, sustainable health care. Made up of more than 140 national health-related organizations and businesses, the NHC's core membership includes the nation's leading patient organizations. Other members include health-related associations and nonprofit organizations including the provider, research, and family caregiver communities; and businesses representing biopharmaceutical, device, diagnostic, generic drug, and payer organizations.

The five areas of focus that PCORI has identified are:

- Increase Evidence for Existing Interventions and Emerging Innovations in Health
- Enhance Infrastructure to Accelerate Patient-Centered Outcomes Research
- Advance the Science of Dissemination, Implementation, and Health Communication
- Achieve Health Equity
- Accelerate Progress Toward an Integrated Learning Health System

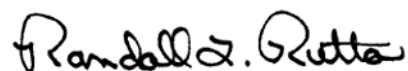
The NHC agrees that these are the appropriate topics and appreciates the comprehensiveness of the list. However, to assure that the promise of these health priorities is fulfilled, the NHC has some specific recommendations about how they might be implemented.

We recommend that PCORI actively work to incorporate the full range of potential patient impacts (e.g., economic burden) that patients experience as the result of disease and/or treatment, not just traditional outcomes (e.g., symptoms, biomarkers). This includes impacts beyond health outcomes, or effects on caregivers and families. This focus on the full range of patient impacts should be infused throughout all the priorities. For example, infrastructure that supports the development of [patient-centered core impact sets](#) could enhance many types of research on existing and emerging innovations.

As part of the NHC's Health Equity initiative, we have identified the need for improved data on demographics burden and other characteristics. Most importantly, our members have identified the need for consistent and comprehensive data, as well as interoperable data infrastructure across health care. Therefore, we encourage PCORI to develop a standard set of demographic, burden, and other data points that will be consistent across PCORI-funded research. This will promote equity because it can allow for easier tracking and identification of health outcomes disproportionately experienced by people from marginalized populations and could provide insights into the causes.

We appreciate the opportunity to provide additional input on these critical issues. Please do not hesitate to contact Eric Gascho, Vice President of Policy and 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.

Sincerely,



Randall L. Rutta
Chief Executive Officer