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May 25, 2022

Collene Lawhorn, PhD
Program Officer, National Institute of Mental Health (NIMH)

Nadra Tyus, DrPH, MPH
Program Leader, Office of Strategic Coordination (The Common Fund)

RE: NOT-RM-22-012. Request for Information (RFI): Challenges and Opportunities in Health and Science Communication Research

Dear Drs. Lawhorn and Tyus;

The National Health Council (NHC) appreciates the opportunity to submit our response to the Request for Information (RFI), regarding opportunities and challenges in health and science communication research.

Created by and for patient organizations more than 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 145 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.

Below are recommendations that can be taken to improve patient health and science communication research.

Communication research to enhance access to, equitable uptake of, and meaningful use of evidence-based health information

The COVID-19 pandemic upended our nation and the world. During these tumultuous times, we observed first-hand the importance of disseminating scientific findings that are timely and supportive through rigorous research. At the National Health Council, we put patients first. We believe that in order for patients to receive correct and optimal information to generate an informed decision, they should be at the center of communication research. Therefore, the NHC recommends that communication research be enhance in the following ways:

- Ensure cultural and linguistic appropriate messaging is at the forefront of dissemination and implementation science and patient care.
- We strongly believe that in order for health and communication research to be meaningful and impactful across sectors, scientific findings should be disseminated via various communication channels in addition to

the peer-reviewed literature. This can be achieved by infusing patient advocates and educators, as well as communication and marketing professionals to the core research team. In addition, the integration of translation and dissemination scientists to the core research team can be vital in the development of policy reports, policy briefs, white papers, data briefs, etc., that are essential to communicating the applicability of science and evidence-based research to an array of audiences, including policymakers.

- We recommend that NIH funding opportunities (R01, K, T and F, U, etc.) require specific dissemination, implementation, and communication strategies in each of their application cycles for new and continuing research projects. This in turn will promote researchers to build communication and dissemination strategies that are patient-centered within the scope of their research proposal beyond the peer-reviewed literature.
- As an organization that is committed to providing a voice for people with chronic diseases and disabilities, it is imperative that researchers capture patient experience data more holistically and in a standardized manner across chronic diseases. The NHC has publicly available resources via our [Patient Experience Mapping Toolbox](#) that can assist researchers seeking to engage patient's experiences before a diagnosis, while getting a diagnosis, and after receiving a diagnosis. Our [Patient Experience Mapping Toolbox](#) was developed with the aim to equip researchers with patient-facing project planning and data collection tools.

Understanding and improving health and science literacy

The NHC understands and supports the integration of science and patient health literacy in all facets of research, including dissemination. For example, we believe that using clear and concise language that is understood by diverse patient populations is of utmost importance. We guarantee that our research tools have been reviewed and vetted by health literacy experts and refined through patient interviews. In 2021, the NHC hosted the [Health Literacy: A Three-Part Series to Support Better Communication](#) to provide our members and community stakeholders communication tools essential for health services researchers and workers. We encourage the utility of our three-part series tools:

1. [Introduction to Health Literacy: Your Clear Communication Toolkit](#)
2. [Health Literacy Strategies for Advocacy](#)
3. [Health Literacy for Science Communication: A Tool to Boost Understanding and Build Trust](#)

Understanding and reducing the spread and impact of health misinformation

The COVID-19 pandemic fueled the spread of health misinformation, vaccine hesitancy, and mistrust in public health. At the height of the Omicron surge, the NHC hosted its virtual [2021 Science of Patient Engagement Symposium](#), themed *Achieving Trust in and Trustworthiness of Science*. Our Symposium brought together over 120 medical, scientific, and research leaders to share their experiences, accomplishments, best practices, and resulting impacts on medicine and science. Dispelling scientific myths and arming patients with accurate evidence-based information, specifically in diverse populations, is pivotal to improving patient and public health outcomes. We urge the NIH to review the summary and list of speakers at our 2021 Science of

March 7, 2022

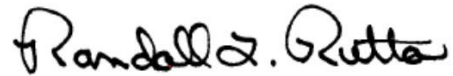
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Patient Engagement Symposium. This will help further the dialogue of patient health misinformation and engage experts in the field to drive patient-centered health policy forward.

Conclusion

We appreciate the opportunity to provide additional input on these critical issues in health communication and research. Please do not hesitate to contact Dr. Omar A. Escontrías, Vice President of Research, Education & Programs, if you or your staff would like to understand more of our tools and resources or discuss this response in greater detail. He is reachable by phone at 520-256-0299 or via e-mail at oescontrias@nhcouncil.org.

Sincerely,

A handwritten signature in black ink that reads "Randall L. Rutta". The signature is written in a cursive, flowing style.

Randall L. Rutta
Chief Executive Officer