

March 7, 2025

The Honorable Robert F. Kennedy Jr. Secretary of Health and Human Services Department of Health and Human Services 200 Independence Avenue, SW Washington, DC 20201

## RE: Urgent Request to Enhance Public Participation in Rulemaking

Dear Secretary Kennedy,

The National Health Council (NHC) believes that public engagement is not merely beneficial for patients—it is essential for Department of Health and Human Services (HHS) itself to make sound, effective policy decisions that reflect the realities of health care delivery and the needs of the American people. The public comment process is an important tool in the partnership between HHS and the patient community. The NHC is concerned that the HHS' recent decision to rescind the Richardson Waiver could signal a decrease in opportunities for patients, caregivers, and other key stakeholders to engage in decisions that affect them.

Created by and for patient organizations over 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, equitable, and sustainable health care. Made up of more than 175 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 and organizations representing biopharmaceuticals, devices, diagnostics, generics, and payers.

During your confirmation hearings, you emphasized the importance of transparency and public participation in government decision-making, stating:

We're going to work together to launch a new era of radical transparency. Only through radical transparency can we provide Americans with genuine informed consent, which is the bedrock and the foundation stone of democracy.

This commitment to ensuring patients, caregivers, and the public have access to essential health information aligns with the administration's stated goal of empowering individuals with clear, accurate, and actionable health care information. However, if comment opportunities on critical issues are limited, it could lead to reduced transparency in HHS decision-making and remove key opportunities for public input on policies affecting federal health programs, including Medicaid, National Institutes of Health grants, public health initiatives, and a wide range of critical issues such as drug pricing reforms, medical research funding, coverage determinations for innovative treatments, Medicare payment and reimbursement structures, reforms to expand access to care in rural and economically disadvantaged communities, strengthening the role of private sector innovation in health care delivery, and efforts to improve price transparency and competition in the health care

marketplace. Ensuring public participation in these areas is essential to crafting policies that support patient choice, encourage market-driven solutions, and uphold responsible stewardship of taxpayer dollars.

The administration has made patient empowerment a central priority. The Executive Order titled "Making America Healthy Again by Empowering Patients with Clear, Accurate, and Actionable Healthcare Pricing Information" (February 25, 2025) affirms:

It is the policy of the United States to put patients first and ensure they have the information they need to make well-informed healthcare decisions. The Federal Government will continue to promote universal access to clear and accurate healthcare prices and will take all necessary steps to improve existing price transparency requirements; increase enforcement of price transparency requirements; and identify opportunities to further empower patients with meaningful price information.

Removing public participation from HHS rulemaking results in HHS having to make policy decisions in isolation, without input from those most affected. We strongly urge HHS to:

- 1. Consider reinstating the Richardson Waiver to reaffirm its commitment to public participation in agency rulemaking.
- 2. Ensure that policies affecting health care grants, benefits, and coverage remain subject to public comment and stakeholder engagement.
- 3. Provide clear guidance on how HHS will incorporate public input in the absence of the waiver.

This change does not just impact bureaucratic processes—it has real-world consequences for millions of Americans and compromises the ability of HHS to craft well-informed, transparent policies that work as intended. Patients, caregivers, and health care providers deserve a voice in the policies that directly affect their access to care, treatment options, and health outcomes. Without meaningful public participation, HHS risks implementing policies that lack critical input from those most affected, leading to unintended consequences and diminished public trust. We urge HHS to reaffirm its commitment to transparency by ensuring that those who rely on federal health programs have a voice in the decisions that shape their care.

We respectfully request a meeting to discuss these concerns further and explore solutions that maintain transparency and protect the voices of patients and their advocates in health policy decisions. Thank you for your attention to this critical issue. We look forward to your response and the opportunity to work together to ensure patient-centered, transparent policymaking.

Sincerely,

Randall L. Rutta
Chief Executive Officer

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