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Robert F Kennedy Jr's proposal to remove public commentary from US health policy is a threat to science and public health

With confidence and trust in science and public health already under pressure, we must double down on transparency and public participation in policy decisions, write Liz Salmi and colleagues

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Since the passage of the US Administrative Procedures Act of 1946, public commentary has remained a cornerstone of US policy making, establishing transparent procedures with which federal agencies must comply.[1] Public comment is not a bureaucratic formality: it's part of a deliberate process designed to ensure accountability in policy making. These mechanisms are foundational to a democratic government reliant on public trust derived from careful and transparent decision making.

That's why a proposal by the new US health secretary, Robert F Kennedy Jr, to eliminate public comment requirements for key decisions in the US Department of Health and Human Services (HHS) is so alarming.[2] If implemented, this change would strip away a critical mechanism that invites patients, care partners, healthcare professionals, and advocacy organisations to weigh in on policies that directly affect them. Removing the formal mechanism for public comment would set a dangerous precedent by permitting policies to be formulated unilaterally behind closed doors.

Public comment has shaped health policy before

Publicly informed rule making is not a symbolic exercise: it has effected positive change in policies over many decades. For example, resistance to transparency in pricing by drug companies moved the US to enact the Sunshine Act, which requires disclosure of payments and gifts from drug companies given to physicians and teaching hospitals.[3-5] This transparency seems to have prompted a shift toward prescribing of lower cost drugs,[6] and other countries followed suit with similar measures.[7]

Another powerful example is the process leading to the nationwide adoption of fully transparent medical records. Stimulated initially by the OpenNotes initiative, a growing number of research and demonstration projects studied the effects of offering patients electronic access to test results and their clinicians' notes. These studies showed that patients felt more informed, reported better adherence to treatment plans, and were able to identify medical errors before harms occurred.[8-11]

Findings by OpenNotes and others influenced development of the information blocking rule, which formalised implementation of sections of the 21st Century Cures Act.[12-14] The proposed rule received over 2000 public comments, and these views helped shape how health information should be shared with patients. In their written response HHS agency authors noted that most commenters, with the exception of health insurers, strongly supported broad access to health data.[15,16] Because the preponderance of comments favoured it, the final rule mandates that patients have this broad access to their health information. Public comment matters because it forces agencies to listen to the people most affected by their decisions, not just to those with primarily political or economic interests.

What happens when transparency is removed?

If Kennedy's proposal progresses, it will allow HHS to make major policy decisions with little transparency or public oversight. This will lead to fewer checks on corporate influence, fewer opportunities for patients and care partners to speak up, and weaker accountability for policies shaping healthcare access, costs, and quality. Without public input, policies would likely favour industry interests, often at the expense of patients.

At a time when trust in science and public health is already under immense pressure, we must not abandon public comment. The covid pandemic showed how misinformation can spread when governments fail to communicate openly with the public.[17] Kennedy has a long record of spreading falsehoods about vaccines and public health, with misinformation likely contributing to declining trust in science.[18,19] Moving now to restrict public input into health policy decisions would further deepen scepticism and erode trust.

When trust is lost, conspiracy theories rapidly fill the void, and we're already experiencing dangerous consequences. This is especially alarming since some Trump administration appointees are the very individuals who have spent years working to undermine the public's trust in medicine and public health.[20] As of this writing, some parts of the US, including western Texas and neighbouring New Mexico, are in the midst of a measles outbreak fuelled by vaccine hesitancy and misinformation.[21] More than 60 people have been admitted to hospital, and two have died.[22] At a moment when confidence in our healthcare system has never been more critical, this makes it even more urgent to double down on transparency and public participation.

The ability to participate in regulatory decision making is not a privilege: it's a legal requirement and a fundamental right in a democratic society. Those who believe in open, accountable governance must

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be clear that public input in health policy is not just important but is essential.

Patient and public involvement statement: The authors of this opinion include a patient advocate, clinicians, and health services researchers.

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The views presented represent those of the authors and not their institutions.

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