

June 1, 2018

To: HHS Secretary, Alex Azar
AHRQ Director, Gopal Khanna
CMS Administrator, Seema Verma
200 Independence Ave. SW
Washington, DC 20201

Dear HHS Administrators,

We are writing to you to express serious concerns regarding your decision to end support for the National Guideline Clearinghouse (NGC), <https://www.guideline.gov/>, and respectfully request that you reconsider your decision, find an alternative means of support, or delay it at least until such a time that the functionality and features of the NGC are represented elsewhere. While we are supportive of modernization and consolidation of federal efforts, it will be harmful to all stakeholders responsible for patient care to suddenly end support for an established and trusted information site necessary for the execution of evidence-based care in both Health IT and clinical practice. Furthermore, we believe that the negative effects on public health, clinical care, and evidence-based medicine will outweigh the possible cost benefits of ending support for NGC.

Key Impacts on the Nation's Health and the Healthcare Ecosystem:

- The Federal government has said they want to expedite the translation of research to evidence-based care at the bedside—removing the NGC would presumably increase the time it takes to execute and limit the ability of clinicians to translate the evidence to meaningful application in patient care.
- Loss of this site takes away the only centralized location that is freely available, easy to understand for users at every level and uses the NAM (National Academy of Medicine) standards on clinical practice guidelines.
- If clinicians do not have easy access to evidence-based information at the point of care, it may increase costs of care and lead to worse patient outcomes in the US population. The NGC helps align the vast expanse of medical literature to support patient-centered and evidence-based healthcare, helping providers to quickly establish the right treatment for the patient and avoiding care which could be unnecessary or harmful.
- The industry will likely see increased costs because commercial, education, and healthcare entities will be forced to use their own resources to search for, obtain, and analyze the content of guidelines rather than being able to use NGC for this purpose.
- The “Patients over Paperwork Initiative” is striving to reduce unnecessary burdens on providers; we believe that the NGC streamlines ability of providers to determine the best practice to implement in the care of their patients. Removing this valuable resource could lead to greater burden on providers towards the outcomes CMS hopes to achieve.

How NGC Is Unique:

No other site follows NAM (previously the IOM) criteria outlined in their 2012 report, *Clinical Practice Guidelines We Can Trust*:

1. Establish Transparency of the guideline development process
2. Manage conflict of interest for all guideline development group members

3. Guideline Development Group composition and development should be diverse and include patients, patient advocates, providers, specialists and other stakeholders
4. To avoid bias, Guideline Development Groups and Systematic Review Writers should not intersect
5. Establish a process for Grading Strength of Evidence *and* Rating the Strength of Clinical Recommendations (systematic reviews given high grades for inclusion)
6. Articulation of Clinical Recommendations should be clear and understandable
7. Establish an external Review Process
8. Establish 3-5 year Update / Review process

NGC accelerates the translation of evidence by requiring a translation plan for all newly posted guidelines. This is a concerted accelerant in the effort to bring guidelines to the bedside faster. Because the NGC synthesizes and summarizes evidence and guidelines, it provides a service to busy clinicians and trainees to help them maintain the standard of care. The NGC, in practice, reinforces and augments the HHS National Quality Strategy and the CMS Quality Strategy.

Why Patients, Providers and Other Stakeholders use the NGC and Impact of Its Loss:

- **Patients and the general public:** utilize this site for understanding their clinical conditions because it is free, centralized, accessible and understandable. In contrast to sites located through a commercial search engine where information is likely to be biased or unreliable, NCG information is well-vetted—**loss of this site may lead to negative health effects and increased health costs through lack of access to patient-appropriate and trustworthy clinical information**
- **Educators and healthcare students:** Physicians, nurses, pharmacists, and allied health professionals in training are encouraged by educators to use the NGC as a source of truth for learning about a health topic and also to compare guidance where there are many conflicting sources of information.
- **Health professionals:** Physicians, nurses, pharmacists, and allied health professionals **use NGC to identify the optimal approach to treatment in a given condition or disease/treatment process.** Guidelines include information on etiology, testing, diagnosis, treatment and prognosis and have a required review period of every 5 years.
- **Clinical organizations:** NGC provides a strict vetting and verification platform for organizations to submit and maintain guideline content for public and multidisciplinary stakeholder use, **which raises the value and improves dissemination of content that they fund and create.**
- **Researchers:** allows for a high-level environmental scan of evidence for point of care practices and **gives information on gaps in evidence that could be a focus for future research.**
- **Consumer health librarians:** provide vetted information from the NGC and other sources to patients and other members of the community to support their health and wellness information needs.
- **Medical librarians:** provide clinicians, clinicians in training, healthcare educators, and researchers carefully selected relevant information, including that from the NGC, to meet their health sciences information needs.
- **Vendors:** obtain information about evidence base, workflow and clinical guidelines for **inclusion in electronic systems, including programming of clinical decision support mechanisms.**

- **Measure developers:** Rely on the NGC for environmental scans of evidence and up to date clinical information **for improved health care measure development.**
- **Government:** currently provides an established platform with the strictest standards for guideline acceptance and posting and **saves costs and time in creating new sites that would duplicate NGC efforts.**

To prevent the closure of NGC from harming the application of evidence-based medicine in practice, we ask:

- **that the federal government continue support for NGC’s current platform of guideline vetting and posting indefinitely, or until a new site has been established and tested that uses the same guideline verification standards with equivalent or better value to the array of healthcare stakeholders described above.**
- **that ongoing funding for NGC (or a new replacement site) should be a protected budget line item to avoid this problem in future years.**
- **that HHS reconsider the value of the NGC to patients and providers and attempt to understand better its established high standards, who uses it for what purpose, and what value that adds to the healthcare community.**

We believe AHRQ has successfully developed and implemented the NGC site and guideline process, but if HHS sees a need to consolidate, we suggest that such a site could be hosted alternatively at CMS, NIH, or even at an external but content-neutral location. In any case, NGC’s format, functionality, and content must be maintained until those requirements are met. We would further argue against management by a “for profit” entity, where organizations pay to post guidelines, as this would automatically cause perceived bias of information.

We appreciate the ongoing efforts of HHS to respond to the needs of the clinical, research, patient, and health IT communities through their attempts to accelerate transfer of evidence, reduce the burden to find trustworthy clinical information, and re-center care around the patient. We hope that you will reconsider your decision to discontinue the National Guideline Clearinghouse to ensure that all healthcare stakeholders continue to have a transparent, evidence-based, centralized location to find and access state-of-the-art knowledge to support evidence-based practice.

Sincerely,

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