



[Home](#) [About](#) ▼ [For Patients](#) ▼ [For Health Professionals](#) ▼ [Research](#)

[Contact Us](#) | [Movement Hub](#) ▼

# OpenNotes Comments on HHS Rule to Improve Patient Access and Interoperability

April 12, 2019

OpenNotes Comments  
on HHS Rule to Improve  
Patient Access and  
Interoperability



In February 2019, the U.S. Department of Health and Human Services (HHS) **proposed a new rule** to support seamless and secure access, exchange, and use of electronic health information. The proposed rule places a strong focus on

patients' ability to access their health information and proposes that clinical notes be included in an expanded set of data that must be exchanged electronically and made easily accessible to patients.

OpenNotes ([www.opennotes.org](http://www.opennotes.org)) provides these comments to help inform decisions regarding the inclusion of clinical notes in the data that must be exchanged and easily accessible to patients in the newly proposed U.S. Core Data for Interoperability.

OpenNotes applauds the proposed rule promoting patient ease of access and greater transparency for medical records. This openness appears to increase patient engagement, trust, and safety, and over time can engender stronger partnerships between patients and clinicians. However, there are many steps between making notes available and having this new practice implemented so that large numbers of patients actually read these notes. With respect to actual note-sharing, enormous variation exists among health systems. In some practices as many as one-third of patients registered on electronic patient portals read their available notes, while in others fewer than 1% of patients participate. Without active patient engagement with their clinical data, including notes, the nation will not reap the benefits of a fully transparent healthcare system.

Building upon 10 years of experience with advocating and assessing the effects of inviting patients to read the notes their clinicians write (see: summary of OpenNotes research findings below), we make the following recommendations to HHS focused both on the specific issue of note sharing and the larger one of bringing greater transparency to the healthcare system:

- Electronic medical records (EMR)/patient portal vendors should be required to provide an option in all EMR products/portals that enables access to notes by patients via secure electronic patient portals and on mobile/cellular devices. The process for accessing notes should be simple and require little in the way of navigation for patients.
- To ensure privacy in special circumstances, information blocking provisions should be implemented to allow health systems and clinicians flexibility to put in place additional privacy protections for patients such as adolescents, patients with mental illness, and victims or potential victims of abuse, including child, elder, sexual, and domestic abuse. Other conditions may also require specified exceptions, depending on individual or group



circumstances.

- EMR vendors should be required to provide functionality in all EMR products that allows practices to calculate: a) the number of patients with active portal accounts opening notes or downloading them to a mobile device; and b) the proportion of all available notes opened or downloaded by patients.
- In order to track the degree to which note sharing is implemented by practitioners, HHS should collaborate on or develop a robust measurement system and scorecard that tracks implementation metrics and the number of patients reading notes and the proportion of available notes read or downloaded at the practice level. HHS should set robust baselines for these measures and include and modify them in future measurement program requirements.
- HHS should establish a “National Transparency Advisory Group” charged with advising HHS and monitoring the nation’s progress toward a fully transparent health care system. The advisory group should be comprised of clinicians, policy makers, patients, experts in health information technology, patient safety, and healthcare organization leaders. In contrast to a focus on health information technologies, the prime concern of the Office of the National Coordinator (ONC) and its advisory groups, the mission of this new group should be to ensure that the goal of bringing more transparency to clinical care is implemented successfully. In particular, it will focus on information sharing designed to increase patient safety and health care value.
- HHS should support learning networks of providers and patients that work to increase the number of providers actively offering shared notes and the number of patients reading their notes. These efforts could focus on: a) regional initiatives; b) vulnerable populations requiring safety net care and/or experiencing literacy or language challenges; and c) patients with a specific or high burden of illness. These networks should highlight clinicians and patients whose exemplary use of transparency can bring best practices to other systems.
- Looking to the future, and taking full advantage of the addition of provenance of information to the EMR, HHS should explore the effects of

notes co-produced by patients and clinicians together and interventions that incorporate transparent quality and price considerations into individual treatment plans to improve quality and value.

- Finally, HHS should include and amplify the voice of patients in building and improving electronic health records and apps enabled by open APIs (application programming interfaces) designed to enable patient and clinician access, management, and sharing of health information.

## OpenNotes Experiences and Findings

OpenNotes, based at Beth Israel Deaconess Medical Center (BIDMC) in Boston, MA, with collaborators around the US and overseas, advocates for and evaluates the spread and effective implementation of shared clinical notes. It studies the effects of this practice on patients, care partners, and clinicians and disseminates its findings. Funded completely through philanthropic support, OpenNotes started in 2010 with pilot demonstration and evaluation studies in the US at BIDMC, Harborview Hospital (Seattle, WA), and Geisinger Health (GH). OpenNotes is not involved in any product development, consulting services or any other commercial activity. OpenNotes and its collaborators have conducted multiple studies, leading to more than 60 publications in the medical literature, and 30 publications by authors not associated with OpenNotes. It has also generated considerable interest in print, broadcast, and social media.

Clinical notes differ from other types of information in the record. They document interactions patients have with their doctors, nurses or other health care professionals and ordinarily contain a summary of the most important information discussed. Notes are “the story” of a person’s health care, connecting the other elements of the medical record. They are separate and distinct from “after visit summaries (AVS)” made available to patients following visits.

Our research and implementation experiences demonstrate that easy access to ambulatory notes brings substantial benefits that outweigh risks for patients and clinicians. Once introduced to the concept of OpenNotes, over 90

percent of patients want easy access to notes to continue, whether or not they may choose to read an individual note. Patients, parents and care partners report many important clinical benefits from reading shared notes, including:

- Better understanding their health conditions
- Feeling more in control of their health
- Better recall of the content of visits
- Improved adherence to medications and their health care plans
- Improved communication with clinicians and care partners
- Increased trust of doctors
- Being reminded of the next steps, such as diagnostic and screening tests, referrals and immunizations
- Finding and reporting potential errors in the record

These benefits cross all populations and clinical specialties. Indeed, among those patients who read notes, patients with lower incomes, African Americans and other racial minorities, and those with less than high school education are more likely than white patients or those with higher incomes to report benefits, and in particular to report improved trust in their clinician and health care organization.

Patients report few risks associated with reading clinical notes. 85-90% report they can read and understand notes. Fewer than 10% report feeling confused, offended, or worried when reading notes. Moreover, confusion also presents an opportunity for clarification, resolution of an error, and other positive outcomes. While privacy concerns are often mentioned by clinicians, few patients report similar worries when it comes to their notes. In fact, they often emphasize that it is their right to have easy access to them.

Clinicians approach the idea of this change in longstanding practice with mixed feelings. While many, moved by the reports of patients, feel offering them ready access to notes is “the right thing to do,” they are anxious about workflow, time spent in documentation, and litigation risks. However, clinicians

who share notes report that workflows are not significantly changed. Once used to the practice, a majority report in surveys that sharing notes is a good idea. Some documentation changes are needed—fewer acronyms, fewer comments that may strike patients as pejorative, reduced “copy and paste” from other areas of the medical chart—but these are quickly integrated into workflows. Evidence also suggests that easy access to notes can increase the safety of care. Patients may find important errors of commission or omission, and they can be corrected before harm ensues. In addition, transparent communication can breed mutual trust, and in a trusting environment, even if mistakes lead to harms, the likelihood of adversarial consequences is likely to diminish.

Five of the largest EMR vendors in the US support note sharing in one or more of their EMR/patient portal products. We have documented the implementation of OpenNotes in more than 200 organizations. More than 39 million people are registered for online portals that share notes with patients. Real world implementation supports our research findings:

- No significant workflow problems have been reported in any implementation. Some documentation issues have required attention.
- Patient and family advisory committees have consistently supported OpenNotes. Patients often describe access to notes as a “right.”
- Multiple surveys by implementers have produced results consistent with OpenNotes research studies.
- Most medical record staff report no change in medical record requests, such as changes in documentation, although we know of no formal study of the impact of OpenNotes on medical record activity.

Some individual patients and patient populations may require special attention:

- As suggested above, clinicians may appropriately wish to “hide” notes in some individual and group special circumstances. Recognizing that the Health Insurance Portability and Accountability Act guarantees patients

the right to the entire record through a formal medical records request process, OpenNotes efforts may not include all notes.

- Access to notes by adolescents varies across the country, primarily due to privacy concerns especially related to parent access and variation in state regulations. OpenNotes may therefore not include all adolescent notes.
- Currently, the majority of OpenNotes implementers do not include notes written by clinicians who focus their practice on patients with mental illness. However, a growing number of psychiatrists, psychotherapists, and other mental health clinicians are sharing notes.

In summary, reflecting extensive experience and research findings, we believe there is sufficient evidence to conclude that the benefits of making notes easily accessible to patients are much greater than the risks. This practice is feasible across the delivery system, with minimal risks of disruption to clinical practice. It can be facilitated by EMR vendors, with modest changes to existing products. The privacy risks to patients appear small. And overwhelming majorities of patients with easy access to notes want such access to continue.



---

#### Related

[A Note From the Director:  
April 2019](#)

April 12, 2019  
In “Blog”

[A Note From the Director:  
March 2019](#)

March 6, 2019  
In “Blog”

[A Note From the Director:  
February 2019](#)

February 1, 2019  
In “Blog”

---

Filed Under: [Blog](#)

---

[News & Events](#)

[Connect & Contact](#)

Sign up for  
emails from us.  
Your

[Latest Tweets](#)

OpenNotes  
supports the



information will  
not be shared.



Beth Israel Deaconess  
Medical Center



HARVARD MEDICAL SCHOOL  
HARVARD UNIVERSITY

SIGN UP



OpenNotes, 133  
Brookline Avenue,  
HVMA Annex, Suite  
2200, Boston, MA  
02215

proposed  
@HHSgov rule  
that places a  
strong focus on  
patients' ability to  
access their  
health...

twitter.com/i/web/  
status/11168...

Yesterday at 9:33  
pm

Heading to  
#ATA19 in New  
Orleans? Look for  
the #OpenNotes  
session with  
@TheLizArmy on  
Monday, April 15:  
"Transpar...

twitter.com/i/web/  
status/11164...

April 11, 2019  
10:38 pm