Sutter Health

OpenNotes Movement: Knowledge Shared = Knowledge[2]

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By Oct. 29, the movement toward greater autonomy and increased healthcare transparency will take another big step forward for Sutter patients. The bipartisan 21st Century Cures Act was signed into law in December 2016, and the "Final Rule" of the Act, which will go into effect in less than two months, includes the following:

"…a provision requiring that patients can electronically access all of their electronic health information (EHI)…"[1] *https://www.healthit.gov/curesrule/*

In this first phase, our patients will be able to see a specified set of data elements from their medical record such as clinical notes, lab and imaging results, as well as problem list, allergies, medications, immunizations, and more.[2] To do so, they will use the Sutter patient portal, My Health Online (MHO), available as a mobile app or via a website. In May 2022, the mandate will be fully implemented and will require *all* EHI that exists to be made available, not just a limited subset.

As an emergency physician, I must admit that when I first heard of this, I experienced a not-insignificant rise in anxiety. I thought, "What if a patient sees my note and disagrees with what I wrote?" "Am I going to get flooded with calls from upset patients?" "What about "sensitive" test results that are released after my patient leaves the ED?" "Will this change my practice for the worse?" Let's take a look.

This part of the Cures Act was written to prevent "information blocking" and to provide penalties for violating the rule. Information Blocking is defined as *"a practice…that is likely to interfere with access, exchange, or use of EHI".*[3] What does this mean in practice? Our notes will be visible to our patients very soon after we finish them, and our patients will be able to see nearly all of their test results, including imaging narratives, either immediately or with little delay. There are four specific exceptions to the immediate release of results, owing to California statute (HIV, Hepatitis, Drugs of Abuse, Pathology), and there are extremely limited exceptions that would allow a clinician, in rare circumstances, to unilaterally block release of notes and/or results.[4]

If the foregoing is causing you anxiety, know that you are not alone. However, an important thing to understand is that patients have had the right to see their entire medical record for many years. The standard process was, and still is, to submit a Request for Information (ROI) to the Health Information Management department. The difference is that going forward, the process will be much easier, more efficient, and a patient won't have to ask for permission. Will a curious patient be more likely to look at their visit notes if they can see them on their iPhone the same day? Perhaps. Will that cause more work or headache for us? Interestingly, I believe the answer to that is no. I say that because of our collective experience with a movement called "OpenNotes."

OpenNotes is an international movement launched in 2010 when Beth Israel in Boston, Geisinger in Pennsylvania, and Harborview in Seattle did an exploratory study in which 105 primary care physicians invited 20,000 of their patients to have electronic access to their clinical notes. After the intervention, few doctors reported longer visits or more time addressing patients' questions outside of visits, 99% of patients wanted OpenNotes to continue, and no doctor elected to stop.[5] There is also recent and local experience with the OpenNotes concept. At Sutter, Valley ambulatory sites have been live with immediate note release for about five years. Over the past year, approximately 7% of Valley ambulatory notes were read by patients, and those practices have not experienced any

significant level of concern or messaging from patients. Many organizations across the U.S. already release notes immediately and similarly have experienced a welcome response from patients and no significant burden on providers. Patients who read notes report that they:

- have a better understanding of their health and medical conditions;
- recall their care plan more accurately;
- are better prepared for visits;
- feel more in control of their care;
- take better care of themselves;
- more frequently take their medications as prescribed; and
- have better conversations and stronger relationships with their doctors.[6]

While it is true that our experience and the research with this level of transparency and ease of access is concentrated in the primary care space, I don't have reason to believe that acute care in the ED or inpatient setting will produce vastly different results. I believe we and our patients will be better served, experience continued benefits as above, and perhaps more that we haven't yet conceived of. Although it's impossible to prove right now, one can hope that, equipped with more knowledge about themselves, our patients may end up with better health outcomes. That would be a win for all of us. Knowledge shared = Knowledge^2.

For more information and tools you can use about OpenNotes and Information Blocking, please visit this resource site.

Tell Us What You Think…

[1] https://www.healthit.gov/curesrule/
[2] US Core Data for Interoperability (USCDI): https://www.healthit.gov/isa/united-states-core-data-interoperability-uscdi
[3] https://www.healthit.gov/curesrule/final-rule-policy/information-blocking
[4] https://law.justia.com/codes/california/2011/hsc/division-106/123100-123149.5/123148/
[5] https://www.acpjournals.org/doi/10.7326/0003-4819-157-7-201210020-00002
[6] https://www.opennotes.org/tools-resources/for-health-care-providers/health-care-professionals-faqs/