New Poll Shows Two-Thirds Of Doctors Reluctant To Share Health Data With Patients

The polling question was simple.

*Should patients have access to their entire medical record – including MD notes, any audio recordings, etc…?*

For many, the response by over 2,300 physicians came as no real surprise.

- 49% – Access to all records should only be given on a case-by-case basis
- 34% – Yes, Always
- 17% – No, Never

In effect, a full two-thirds (66%) were clearly reluctant to share health data with their patients. A significant 17% were completely opposed to the idea outright – ever.

It’s an important question because while there’s been a fair amount of criticism recently toward competitive software vendors in healthcare (a.k.a. “information blockers”), there’s been little insight into the sentiment on the part of the actual authors of the data – the doctors themselves. Individual opinions are both anecdotal and varied, so this represents the first poll of physician’s directly and was conducted through the large physician social network known as [SERMO](#).

SERMO is a leading – if not the largest – social network exclusively for physicians. A key feature of the network is being anonymous, which fosters the open exchange of information, insight and second opinions within a large clinical network with no risk of recrimination. I’ve written about the value of patient anonymity before ([here](#)), and SERMO is applying similar benefits of social networking among physicians. [*NB: Poll results were verified by Sermo sources but are not publicly available]*

The statistics behind the SERMO network are key to understanding the scale and value of clinical opinions collected through it – even if the process isn’t scientific.

- About 305,000 US doctors are SERMO members (~40% of American physician community)
- About 38,000 UK physicians are members (~16% of UK physician community)
- 3,500 challenging patient cases were posted to the network by doctors last year
- These patient cases were viewed 700,000 times and received 50,000 comments

The results do reflect a strong clinical reluctance to share health data with patients. Commenting is also available as part of the poll — here’s a sampling of two opposing comments that received the most number of votes considered “helpful.”

*Internal Medicine Doctor* from United States

*No they should not have access to their full records. Many times they contain clinically useful information for patient management that may be offensive but true. Some people can’t handle the truth and that will lead to vilification*
of the physician. Full access also means generating questions for which there is no time to lecture the patient. I have on more than one occasion been forced to explain as though I could bring all my understanding from years of practice to a patient who recreationally reads about health care. The records remain private property of the physician who generated it for the care of the patient. If the patient doesn’t like that fact then they can go elsewhere. (9 physicians found this comment helpful)

**Psychiatrist** from United States

Yes. Full access. (5 physicians found this comment helpful)

Those were the results from inside the SERMO network, but I also wanted to capture opinions after the poll. Defending the clear reluctance was this argument.

Most patients never really need to see a full electronic medical record because much of the information doctors enter is tied to reimbursement and regulatory requirements. That often makes a full record hard to decipher and why most electronic health record software allows patient access to the most important elements as a snapshot through a patient portal. A full record – taken out of context – with no opportunity to help translate and decipher the clinical information can easily lead to wrong and painful conclusions very quickly. That’s why the most popular answer to the question was for the doctors themselves to make that decision on a strictly case–by–case basis. Steven Campau, MD – General Practitioner/Internist and SERMO member

An opposing view (by a doctor who does share all his patient data – including clinical notes) was a compelling rebuttal.

It profoundly changes the nature of the relationship. If the record (or visit note) is written explicitly as a shared document, it is no longer possible to maintain a relationship based on asymmetric power. I can no longer keep secrets. If there is an issue or potential issue impacting care, I have to address it with the patients. This is often what clinicians find objectionable. The thinking is “how can I document that I think the patient is being unreasonable or that depression is contributing to their pain or that their report of symptoms is exaggerated if they will see it?” This is exactly why I think it is so important. Hiding these issues and using them to alter care without involving the patient is manipulative and paternalistic and keeps the patient from being fully autonomous. Peter Elias, MD – Family Medicine and SERMO member

Sharing physician notes is the key focus of a project called OpenNotes that was launched about 5 years ago. So far, about 5 million Americans (about 1/3 through Kaiser and the VA) have ready access to all their patient data – including clinical notes.

I’m not the least bit surprised at the results of the poll. As the OpenNotes movement grows we see several reasons for physician hesitation to share clinical notes. Predominant is simply fear of change itself, and in particular of more work that might ensue. Some docs are just plain embarrassed by the quality of the notes they write; the English may be bad, or the spelling wrong. Some are afraid of scaring their patients (although
patients report this rarely happens). The final one, unspoken and unpleasant, involves truth itself. Provoked by RVUs and the craziness of payment schemes, patients will see a note that says the clinician did a full exam and discussed multiple issues over the course of 40 minutes when, in fact, they know the 5 minute visit was hands off. Nevertheless, doctors grow to like the practice once they give it a try, and patients love it and report clinically important benefits. Those who read notes also say the presence or absence of their availability will very much guide their choice of a future provider. So we’re optimistic that it in time it will become the true standard of care.

Consider this: Epic Systems has already made open notes the default in their new installations! **Tom Delbanco, MD** – Professor of Medicine, Harvard Medical School and Beth Israel Deaconess Medical Center (and Co–Director of the OpenNotes Project)

Given all the recent criticism around “information blocking” (which I also covered here), that last sentence is worth repeating.

**Epic Systems has already made open notes the default in their new installations.**

In his recent book *The Digital Doctor*, Dr. Bob Wachter dedicated an entire chapter to the topic of OpenNotes. The chapter is a balanced clinical assessment of the enormous challenge at the very center of this fragile dialog. It’s a foundational component to the relationship and the inclination for protective self–censorship on both sides is very real. Paper afforded reasonable patient privacy where files and folder were tethered to a facility that was often secure and hard to access by anyone. As we’re all learning, healthcare is a prime target for cyber criminals (nation state or otherwise) and digital records (at scale) have quickly become easy/preferred targets.

The recent swarm of mega data breaches in healthcare has resulted in about 96 million records stolen – in fewer than 12 months. The consequences for patients who have their medical identity stolen can be financially damaging and even life-threatening. The path to full legal remediation is often unknown and untested. Included in these breaches are millions of kids who likely won’t know the full effect for years to come – and the effects themselves can be lifelong.

The federal law known as HIPAA will penalize healthcare institutions for the breach itself, of course, but large healthcare entities all have layers of cyber insurance for financial protection. Anthem, for example, had between $150-$200 million in cyber insurance through at least 6 layers of insurance protection. [*Disclosure: Our family was among those potentially affected by the Anthem breach.]*

Patients, on the other hand, have very little real protection (or recourse) against these sizable risks. Patients are also likely to be embarrassed by clinical conditions that need to be disclosed – in some cases to complete strangers that may be arbitrarily assigned through the annual lottery of “in-network” provider matching.

Similarly, doctors are less likely to include factually correct medical notes that facilitate their treatment of patients over long intervals – and that may also help their colleagues with patient treatment.

**On top of that, many of my notes include a differential diagnosis, the list of possibilities that doctors learn to create in every case. But how will a patient handle “Probable viral infection, but need to rule out HIV, rheumatologic**
disorder, and malignancy”? That is good medicine, yet I might not write it if I knew that the audience included the patient himself. Robert Wachter, MD
– The Digital Doctor

Should patients have access to their entire medical record? It’s a simple question, all right, but the answer – like so many others in healthcare – is both complex and controversial. In the end, the most reasonable voice for our collective digital health destiny may well be the one I read in Dr. Wachter’s book.

Patients possess a body of knowledge about themselves that we can never hope to master, and we have a body of knowledge about medicine that they can never hope to master. Our job is to bring these two groups together so that we can serve each other well. Tom Delbanco, MD in The Digital Doctor by Robert Wachter, MD

Serving each other well is the right objective and digital health records (at scale) are clearly able to help with that objective. What’s actually in the health record and who has access to it represents at least one critical debate ahead. Based on this recent SERMO poll, about 66% of physicians are reluctant to share all their patient data – and that does represent a sizeable (and to this point unknown) majority.