

# Do You Own Your Healthcare Data? Not According to Government or Healthcare Businesses



By *Chuck Dinerstein* — November 1, 2018



Courtesy of [mcmurryjulie](#) [1]

Interoperability - the ability of physicians and health care systems to share electronic versions of patient information. The portability of today's patient's electronic medical record is not anywhere as easy or transparent as copying the chart, handing it to the patient and letting them take it to a new provider - a 1980 technology. It turns out that unlike analog records, digital records stored in proprietary formats are not easily shared - despite the explicit statement in the federal funding of EHR systems that they "Improve care coordination, and population and public health."

Software companies that acquired millions of taxpayer's dollars to develop proprietary software and then additional millions for the "rent" of annual maintenance and upgrades dragged their feet in creating translators allowing information to pass seamlessly between health systems and physicians using different EHRs. When care is "transitioned," from one physician to another, or from hospital to a post-discharge nursing facility medical mistakes concerning medications and continuing treatment occur, threatening patient safety and health outcomes. After all, if you are hospitalized and then discharged home, what records does your primary care provider receive about your hospital stay? Does she know of medication changes? Thirty plus years, billions of dollars and countless wasted hours of physician and other providers time later and we still cannot duplicate let alone improve the 1980 approach.

You would think that these titans of software, with revenues in billions of dollars, would be able to provide a mandated system requirement to share information between providers. The current excuse for lack of transportability – the Stark law, specific federal anti-trust regulations.

## Stark Laws

This legislation written last century prevents ‘kick-backs’ between referring physicians or entities. The Stark laws are designed to prevent Dr. A from referring a patient to Dr. B and receiving some financial remuneration or from referring that patient to Lab or Facility C in which Dr. A has a financial interest. Patient referrals should not result in an exchange of “value” between the sender and receiver; that prevents a conflict of interest and is a guide rail for meeting our fiduciary responsibilities to patients. But what value are we exchanging when we transfer patient records?

Government and business agree, your healthcare data has value. If that is puzzling to you, consider the value of the data you provide to Facebook, Google or Apple. But who is the owner of that data? It turns out if you consider both the government’s and health systems’ position, the data is owned by them, not the patient. Here is a portion of a letter sent by a software executive [1] to the Office of the Inspector General for Health and Human Services regarding interpretation of the Stark Law.

*“In healthcare, however, because the transfer of patient data occurs most frequently in the context of a care referral, any accompanying transfer of value is prohibited under the Stark Laws and/or the Anti-Kickback Statute. As a result, the owner/curator of quality data is obligated to assume the cost of electronic transfer of information to a recipient. The beneficiary of the work and the infrastructure investment necessary to curate that data and enable the secure and efficient transfer of the data—the recipient—is prohibited from paying fair market value for that work and investment. This paradigm, which forces the curator of data to pay for the privilege of sending data electronically to a recipient, operates as an effective economic disincentive to information sharing in healthcare. That disincentive, of course, burdens clinicians and impedes efficient delivery of high-quality care to millions of Medicare beneficiaries.”*

Too jargon-filled? Here is the same author quoted in [Modern Healthcare](#) [2],

"There is a cost associated with building and maintaining the technical infrastructure. ...Our proposal would allow for the recipient of valuable data to compensate for the real cost incurred in curating and sending that data electronically."

Who would receive this compensation? The same software people who were supposed to provide this functionality previously; greater “administrative” costs will let these companies once again dine on our dime. But there is a greater injustice perpetrated. Who decided that this valuable data, belongs to the health system?

### Who owns your healthcare data?

More than any information we have, our healthcare information is deeply personal and ours alone. If the patient owned their data, there would be no exchange of value between sender and receiver,

the value would be retained by the patient. We would not need to carve out a regulatory exception or write more regulations.

Healthcare data is collected from our speech, our blood, our tissue or the assessments of physicians in our "employ," (after all we are paying for the service). When was it decided that this data belonged to the health system "collectors ?" At least Facebook, Google, and Apple provide terms of service that we don't read, here there is no pretense of consent at all.

Physicians have no problem sharing information, ask any physician whether he gets a note from the doctor he recommends to his patients; because if not, he finds another consultant. To understand this data "gold rush, follow the money. It leads back to software vendors looking for a "rent hike," and health systems that are trying to retain "lives at risk" from their competitors by making transport of records more difficult.

[Seema Verma](#) [3] CMS administrator, in addressing this issue said:

*"Let me be clear, we will not achieve value-based care until we put the patient at the center of our healthcare system....it's not acceptable to limit patient records or to prevent them and their doctor from seeing their complete history outside of a particular healthcare system."*

The first step is to say as a matter of principle, that healthcare data is the property of the individual to share as they believe necessary. Who will stand for our rights?

[1] [Greg Carey](#) [4] Director Government & Regulatory Affairs Athenahealth, Inc

Sources: [Athenahealth asks the OIG to permit a market for health data](#) [2] [Athenahealth floats kickback carve-out that would allow physicians to pay for clinical data exchange](#) [5]

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**Links**

[1] <https://pixabay.com/en/ehr-emr-electronic-medical-record-1476525/>

[2]

[https://www.modernhealthcare.com/article/20181030/NEWS/181039980?utm\\_source=modernhealthcare&utm\\_medium=NEWS-181039980&utm\\_campaign=am](https://www.modernhealthcare.com/article/20181030/NEWS/181039980?utm_source=modernhealthcare&utm_medium=NEWS-181039980&utm_campaign=am)

[3] <https://www.cms.gov/newsroom/press-releases/speech-remarks-cms-administrator-seema-verma-himss18-conference>

[4] [https://s3.amazonaws.com/assets.fiercemarkets.net/public/004-Healthcare/external\\_Q42018/OIG\\_RFI\\_-\\_Anti-Kickback\\_Statute\\_-\\_athenahealth\\_comments.pdf](https://s3.amazonaws.com/assets.fiercemarkets.net/public/004-Healthcare/external_Q42018/OIG_RFI_-_Anti-Kickback_Statute_-_athenahealth_comments.pdf)

[5] <https://www.fiercehealthcare.com/tech/athenahealth-cerner-chime-hscc-oig-anti-kickback-statute-data-ehr-cybersecurity>