

Patient Consent and the Commercialization of Lab Data



Article: Adam Tanner

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Guest: Adam Tanner is writer and resident at Harvard University's Institute for Qualitative Social Science and the 2016-17 C.W. Snedden Chair in Journalism at the University of Alaska Fairbanks.

Bob Barrett:

This is a podcast from *Clinical Chemistry* sponsored by the Department of Laboratory Medicine at Boston Children's Hospital. I'm Bob Barrett.

In essentially every action we take, data are gathered and transmitted to companies that are used for making predictions about our interest and future actions, among other things that enhanced their business and operations. Healthcare consumers may not realize that there is also interest and ongoing activity in using their de-identified medical information in similar ways.

Proponents argue that this information exchange is a critical aspect in advancing patient care and the healthcare industry. Others are concerned about the potential for breaching patient confidentiality and the lack of transparency around such transactions and their financial value. There are also differing opinions around who owns de-identified medical data.

In a new book titled *Our Bodies, Our Data: How Companies Make Billions Selling Our Medical Records*, Dr. Adam Tanner reveals how "middleman companies," connecting pharmacies, doctors, hospitals, and insurance companies, are making huge profits selling anonymized personal details about health consumers' medical conditions. He provides his opinion on patient consent and the commercialization of lab data in the February 2017 issue of *Clinical Chemistry*, and joins us for this podcast.

Adam Tanner is Writer-in-Residence at Harvard University's Institute for Qualitative Social Science, and the 2016-2017 C.W. Snedden Chair in Journalism at the University of Alaska, Fairbanks. So tell us, how is lab data sold commercially?

Adam Tanner:

So lab data is sold commercially, something that would be a surprise to most people who go in to have a blood test or urine test, and indeed a surprise to many people who work in those labs, because they're often not informed that there is a commercial secondary market trade in patient data.

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- Bob Barrett: So, what patient data is being sold?
- Adam Tanner: Patient data across the spectrum of healthcare is being sold and that means you go to the doctor, the door is closed, you tell the doctor your medical issues, the doctor writes it down in electronic medical health record system, the doctor sends perhaps a copy of a prescription to the pharmacy. Those transactions are recorded by the secondary companies, by the pharmacy and others, and that information may be sold. The doctor may send you to get a blood or urine test. That information may be sold. The insurance companies that cover the costs of these various transactions, they may sell that information. Your name will be removed from those transactions. It will say, "Patient this age, this gender, who lives in this part of town and who goes to this specific named doctor." All of that is a multibillion dollar commercial trade.
- Bob Barrett: And who is doing the buying and selling?
- Adam Tanner: The buying and selling -- the selling comes from the middlemen who handle the data, the electronic health records companies, the insurance companies that process the claims, the labs, so that would be the big lab names such as LabCorp, Quest, and others, pharmacies--CVS, Walgreens, other major pharmacies. Those are the suppliers of the data, as well as middlemen you've never heard of.
- The buyers are largely the pharmaceutical companies who want to better sell and market their drugs, but there's also people such as investors on Wall Street who are trying to get insights on which drugs are selling well. And as I said, this is not only in the United States. It's a big multibillion dollar trade internationally.
- Bob Barrett: Well, let's talk about how big it is. How big is this total business in patient data?
- Adam Tanner: Well, the largest data mining company is called QuintilesIMS. They're a company worth nearly \$20 billion. Now, the amount of money made by any particular entity will vary greatly. So, for a lab, they may make single digit millions; a pharmacy, a large pharmacy chain, may make tens of millions of dollars, and then worldwide this all adds up to billions of dollars. Some other names of companies that may be familiar to people would be LexisNexis, the big database company that's known for their legal and other services, IBM Watson Health has files on hundreds of millions of patients. Some of the commercial insurance companies have also set up their own divisions that sell the data and so those companies would be ones known to many people.

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Bob Barrett: Do patients have a say in determining what happens with their medical information, and should they have a say?

Adam Tanner: Right now, patients don't have a say and indeed they don't know about this trade in secondary data. The data once anonymized is not considered your data, so you don't have a say in what happens to it.

Bob Barrett: And do you think in your opinion that, that should change?

Adam Tanner: I think there are growing risks of having data in wide commercial circulation and I do think it should change. I think patients should have the ability to decide for themselves what happens with their information, whether or not it's anonymized.

So, imagine some of the things you do that are very private. You go to perhaps a religious figure and you may give confession or speak to them personally. That's a conversation you wouldn't share with others.

The same if you visit a lawyer or an accountant, these are personal, intimate conversations. Now, it might be really interesting for social scientists and others to get their hands on information that's anonymized from people, but it would undermine the confidence in the system. And I think that's ultimately the problem with this big commercial sale is that when patients understand that their information is for sale at every point of the healthcare system, their confidence in revealing all of their issues to healthcare providers will be undermined.

Bob Barrett: Even though this data is anonymized, are there still dangers to privacy with medical information in commercial circulation?

Adam Tanner: Many years ago, before computing was very fast and when storage was very expensive, the risks were far less. Nowadays though, as companies gather what is called longitudinal patient data, information about you going back years, it's easier and easier to get clues as to who is who. As I mentioned before, there is some information about you already in anonymized files. It may include a year or date of birth or gender, full or partial zip code and the name of your doctor. Now, if you put all of that information together over years, there are bigger clues.

So, for example, I'm talking to you now from Fairbanks, Alaska, where I'm teaching at the university for a year. If you knew that I had medical care delivered here or gotten prescriptions or other things, as well in my previous cities, I might be identifiable, because before this I lived in the

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Boston area, in Cambridge, Massachusetts. And before that I lived in Belgrade, Serbia. So, I might be the only man of my age who meets that three-city pair that had medical help or visited a doctor in those various places.

It seems abstractly very hard that you could be identified but clues over time, like that, will allow outsiders to use the data.

Bob Barrett: So, you figure a database like LexisNexis might be able to narrow you down?

Adam Tanner: Right. Now, again, the commercial purposes for which they use it is not about re-identifying patients and they specifically say to their client you shouldn't re-identify it, but there are other who may try to take this information for purposes that are less -- less commonplace than marketing and sales, which is the overwhelming use of the data. You could have adversaries that want to use the data. You could be discriminated against. It could be a high-level thing from the President of United States down to a common person, but this information about you that's in circulation could be damaging if others could get their hands on it.

Bob Barrett: Well finally, looking ahead, do you see any sort of protest going on against this sort of thing or is this just going to continue?

Adam Tanner: The reason why I've written this book called *Our Bodies, Our Data* which just came out is I would like to encourage a public discussion and debate about the issue. And in that discussion, think about what's the best way to handle our medical data in the future. What's happened now, we have a system in which commercial companies have decided for themselves what's best for the market and for patients and everyone else. This trade is legal. It's allowed under the HIPAA rules, but it's one in which the people receiving healthcare and indeed many doctors, many nurses and others working in the system do not know about.

So, my thought is, it's hard to have an intelligent public discussion about what's the best system for us all, when vast swaths of the population do not know about this trade. I think we should have a discussion as to whether or not to strengthen the privacy protections, to make patients in control of all of their data, whether or not it is anonymized. At the same time, I think that there should be a discussion of how to encourage science and research to use this data, but I think patients should be given the choice. The same way if you want to contribute to charity, you have that choice as to when and to whom you want to give your money. I think there should be that choice when it comes to your medical data.

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There's many fine medical researchers, universities, and various institutions, who are trying to solve disease and trying to come up with cures. Many people would volunteer and happily participate in getting their information to them, but I think they should have the choice, and right now we don't have the choice and we don't even have the discussion of what's going on because the trade and patient data is so opaque.

Bob Barrett: Is this trade used to develop new drugs, new cures, or is it just a marketing thing?

Adam Tanner: The companies such as QuintilesIMS, Symphony Health, and others who are the big data miners, they say that this trade will help science and will help lead to major medical breakthroughs in curing disease and coming up with new cures.

So far, however, when you ask these companies and officials involved in these businesses, they cite interesting analysis, interesting cost benefits, and so on, but no major breakthroughs. Still, the standard of scientific research remains a double-blinded test of two different groups of patients taking different medications, studying specifically in laboratory conditions. So, although it's not impossible that we will have breakthroughs from the big data from patients, what happened so far is it's used overwhelmingly for sales and marketing.

Bob Barrett: There doesn't seem much of a way of putting that genie back in the bottle, or does there?

Adam Tanner: Well, if you redefine the rules to say that patient data is any information about patients, whether or not it's anonymized, then you would put patients back in control. Again, many of these data brokers will have businesses to do as consultants and providing insights on the market, there could still be a lively business in that kind of work. There can still be research going on in medical institutions. I think it's just a healthier approach and a safer approach as we go forward in time.

Bob Barrett: Adam Tanner is Writer-in-Residence at Harvard University's Institute for Qualitative Social Science and the 2016-17 C.W. Snedden Chair in Journalism at the University of Alaska Fairbanks. The name of his book is *Our Bodies, Our Data: How Companies Make Billions Selling Our Medical Records*. We thank Adam Tanner for being our guest in this podcast from *Clinical Chemistry*. I'm Bob Barrett, thanks for listening.