



# Your private medical data is for sale - and it's driving a business worth billions

**Although information is anonymized, data miners and brokers can build up detailed dossiers on individual patients by cross-referencing with other sources**

**Sam Thielman** *in New York*

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Your medical data is for sale - all of it. Adam Tanner, a fellow at Harvard's institute for quantitative social science and author of a new book on the topic, *Our Bodies, Our Data*, said that patients generally don't know that their most personal information - what diseases they test positive for, what surgeries they have had - is the stuff of multibillion-dollar business.

But although the data is nominally stripped of personally identifying information, data miners and brokers are working tirelessly to aggregate detailed dossiers on individual patients; the patients are merely called "24601" instead of "Jean Valjean".

At the doctor's office, Tanner told the Guardian, "you close the door and you think, I'm telling my doctor my most intimate medical secrets, and only my doctor knows about it. But it's sold commercially." Patients are reduced to gender, age, particular ailments and neighborhood. Then, Tanner said, data miners cross-reference that information with data from pharmacies about who they sell prescriptions to, culled by big drugstore chains like Rite Aid and CVS.

In a new report from the Century Foundation released on Tuesday, Tanner quotes Per Lofberg of CVS: "The patient is not really a component of this because their name and connection to the prescription have been stripped off."

But other forms of data, such as information from fitness devices and search engines, are completely unregulated and have identities and addresses attached. A third kind of data called "predictive analytics" cross-references the other two and makes predictions about behavior with what Tanner calls "a surprising degree of accuracy".

None of this technically violates the health insurance portability and accountability act, or Hipaa, Tanner writes. But the techniques do render the protections of Hipaa largely toothless. "Data scientists can now circumvent Hipaa's privacy protections by making very sophisticated guesses, marrying anonymized patient dossiers with named consumer profiles available elsewhere - with a surprising degree of accuracy," says the study.

"The problem over time is that as you have more and more information, there's more and more about people who might be," Tanner said. He has lived in two different cities recently, he said; now he will teach for a year in the small city of Fairbanks, Alaska - population roughly 32,000. On an index that cross-references people who have lived at addresses in all three cities over a five-year period - an easy-to-find set of data - the researcher said he could easily be the only entry.

Tanner said that non-medical data, which people might consider less private, is in fact easier for the owner to control. "You could try to choose your doctor based on what systems they use and whether [those systems] sell your data commercially, but often you have insurance through your employer and you don't have a choice."

Many companies trade in medical data - IMS Health is the one Tanner names most prominently in the Century Foundation report, but IBM Watson and General Electric also have businesses in patient info.

The legal right of businesses to harvest and sell the information of individual patients without their permission has been upheld by the US supreme court, thanks to a case in which conservative justices ruled in favor of IMS Health and against the attorney general of Vermont. In 2011, the high court struck down a Vermont law restricting the sale, disclosure, and use of records that revealed the prescribing practices of individual doctors, ruling that corporations' right to free speech trumped individuals' right to privacy.

"We need to discuss this," Tanner said. "[Data miners and brokers] often don't want to talk about it because it's a multibillion-dollar trade and they say there's a great chance to advance medical science. They don't talk about the real reason, which is marketing and sales."

The question of whether or not to use individual medical data in the interest of private corporations should be up to those individuals, Tanner concluded. “If there’s a chance to advance medical science, let them make the case to we the patients. If you want to donate your data to science, that’s great, but you should have the choice. Right now, we don’t have the choice.”

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