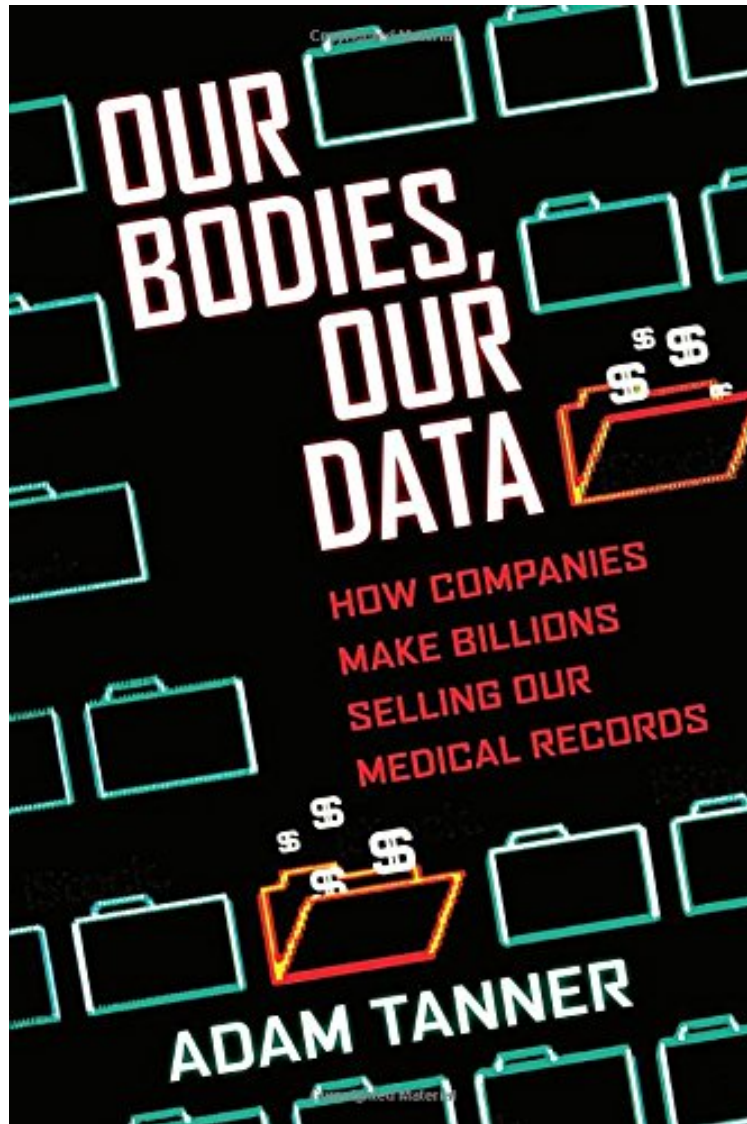


(Download free ebook) Our Bodies, Our Data: How Companies Make Billions Selling Our Medical Records

Our Bodies, Our Data: How Companies Make Billions Selling Our Medical Records

Adam Tanner

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Adam Tanner : Our Bodies, Our Data: How Companies Make Billions Selling Our Medical Records before purchasing it in order to gage whether or not it would be worth my time, and all praised Our Bodies, Our Data: How Companies Make Billions Selling Our Medical Records:

0 of 0 people found the following review helpful. He is right, and it is even worse than he was able to verify.By Nancy

A This book is the result of a masterful investigation of the hidden world of data mining. It is hard for me to review objectively because I am so grateful to have something solid to confirm what I have suspected all as the result of various bits of information I have picked up here and there. My only disappointment is that he did not get more data about some of the other ways this data is being sold to our detriment. HIPAA tries to make us feel our health care data is secure, but HIPAA is actually facilitating the invasion of our privacy in this day and age of big data. The breadth of the definition of "healthcare operations", the lack of enforcing the "minimal data necessary" rules, the insufficient de-identification rules and the insufficient scope of the protection are being ignored to feed the hungry data miners, which includes our own government. 1 of 1 people found the following review helpful. Ripe for Disruption By Raj Sharma Thorough investigative journalism. Really sheds light on the dark alley of medical data brokering. Also gives hope that something can be done. Patient consent, opt-in opt-out registries, patient awareness, mandates, and laws can prevent medical data trafficking. However, it will require that patients start treating their healthcare data as an asset similar to financial assets. It is not clear how big this market is. Market cap of one or two data brokers gives some idea about the size of this industry. Also, if the individual data is only worth \$3-\$7, it is hard for patients to treat their medical records as a valuable asset. Nevertheless, it should make all of us furious that someone else is benefiting from selling something that belongs to us and doing so without our knowledge and consent. 5 of 6 people found the following review helpful. "Our Bodies, Our Data" breaks the incredible story: HIPAA is NOT a Privacy Rule. No health data is private in the US. By Deborah C. Peel, MD, Founder President, Patient Privacy Rights "Our Bodies, Our Data" finally breaks the incredible story that HIPAA is NOT a "Privacy Rule" at all: the US health technology system enables the sale, disclosure, and use of sensitive medical records without patient consent. 92% of the US public expects to control which personal health records are private, which are shared, and who sees them. But today no personal health data can be kept private in the US, or most of the developed world. This is the 1st ever book on the massive, hidden, global health data broker industry. Adam Tanner interviewed hundreds of experts to piece together this deeply researched and eminently readable history of an unknown, secretive, very lucrative industry. Quintiles IMS is valued at \$20 billion USD; its existence would be impossible without access to all patient health data. Chap. 1 opens with my discovery that US pharmacies were selling prescription records in the 90s, violating our human civil rights to health privacy. The following chapters are engaging vignettes of the key figures who built the secretive health data broker industry, and Tanner's investigation of Quintiles IMS, the world's largest health data broker. It buys, sells, trades many nations' health data with 100,000 health data brokers covering 780,000 daily data feeds to update longitudinal, detailed profiles of 530 million people. This huge, invisible industry uses personal health data to conduct research, to develop new products and services, and to market to customers (companies and patients). The data broker industry is also the primary beneficiary of \$30 billion in stimulus dollars the US invested in health technology. Not patients. Opening commercial use of the nations health data was naively expected to spark path-breaking new research, novel treatments, and cures. So far, it hasn't. Meanwhile patients and doctors can't gather complete health data for treatment. Medical records were originally designed to help physicians treat sick people, but current US health technology systems were designed to help industry and government. Why didn't we buy technology that ensured patients right of consent and privacy so they could trust and speak freely with doctors? Tanner closes by making the case for the right of consent, which enables privacy. Without privacy, patients withhold sensitive information, literally putting their health and lives at risk. The highest ethic in Medicine is to save a life. Next is do no harm? Shouldn't health technology also do both?

How the hidden trade in our sensitive medical information became a multibillion-dollar business, but has done little to improve our health-care outcomes Hidden to consumers, patient medical data has become a multibillion-dollar worldwide trade industry between our health-care providers, drug companies, and a complex web of middlemen. This great medical-data bazaar sells copies of the prescription you recently filled, your hospital records, insurance claims, blood-test results, and more, stripped of your name but possibly with identifiers such as year of birth, gender, and doctor. As computing grows ever more sophisticated, patient dossiers become increasingly vulnerable to reidentification and the possibility of being targeted by identity thieves or hackers. Paradoxically, comprehensive electronic files for patient treatment the reason medical data exists in the first place remain an elusive goal. Even today, patients or their doctors rarely have easy access to comprehensive records that could improve care. In the evolution of medical data, the instinct for profit has outstripped patient needs. This book tells the human, behind-the-scenes story of how such a system evolved internationally. It begins with New York advertising man Ludwig Wolfgang Frohlich, who founded IMS Health, the world's dominant health-data miner, in the 1950s. IMS Health now gathers patient medical data from more than 45 billion transactions annually from 780,000 data feeds in more than 100 countries. Our Bodies, Our Data uncovers some of Frohlich's hidden past and follows the story of what happened in the following decades. This is both a story about medicine and medical practice, and about big business and maximizing profits, and the places these meet, places most patients would like to believe are off-limits. Our Bodies, Our Data seeks to spark debate on how we can best balance the promise big data offers to advance medicine and improve lives while preserving the rights and interests of every patient. We, the public, deserve a say in this discussion. After all, it's our data.

Tanner is a persistent and experienced researcher...and the information he gleans paints an alarming picture...A thorough report, carefully researched and well-documented, aimed at both general readers and policymakers. Kirkus sPatient data presents both promise and peril. Important public and private interests hang in the balance as consumers, providers, advocates, industry actors, and governments weigh increased transparency, informed consent, privacy issues, and the right to know. In *Our Bodies, Our Data*, Adam Tanner tangibly advances a vital conversationadroitly articulating choices that may profoundly shape the future of health and health care. A. Eugene Washington, M.D., Chancellor for Health Affairs, Duke University, President and CEO, Duke University Health System Adam Tanner has thoroughly researched how big pharma continues to trample on our medical privacy. This is a terrifying and strongly-argued account of how drug companies collect, analyze, and sell patient data and a must-read for anyone who has ever been to a doctor. J. Kyle Bass, Chief Investment Officer, Hayman Capital Management About the Author Adam Tanner is writer in residence at Harvard University's Institute for Quantitative Social Science and the author of *What Stays in Vegas: The World of Personal Data*, *Lifeblood of Big Business* and *the End of Privacy as We Know It*, which the Washington Post named one of fifty notable works of nonfiction in 2014. Tanner served as a Reuters correspondent from 1995 to 2011, including as bureau chief for the Balkans (2008-2011) and San Francisco (2003-2008). He was also posted in Berlin, Moscow, and Washington, DC. He has appeared on CNN, Bloomberg TV, MSNBC, CNBC, NPR, the BBC, and VOA; has written for magazines including *Scientific American*, *Forbes*, *Fortune*, *MIT Technology* , and *Slate*; and has lectured across the United States and internationally. For the 2016-17 academic year he is the Snedden Chair in Journalism at the University of Alaska Fairbanks.