

WHO USES MY HEALTH DATA?

1 PRIMARY DATA SOURCES



THE PROVIDER GROUP

medical encounter note including name, dob, diagnoses, prescription, doctors name, when and where I saw my doctor, etc.
Many provider groups sell de-identified patient data.

THE PHARMACY

my prescription includes my name, dob, my doctor's name, medication, dose, etc.
75% of all retail pharmacies "send some portion of their electronic records" to at least one data miner.¹¹

THE LAB

my blood sample and identification including my name, dob, sex, ordering physician, etc.
In 2015, nearly **1/2** of all labs send data to Iqvia (was IMS), labs send data to other data miners as well.¹³

MY INSURER

medical claim from my provider to my insurer including the coded services provided during the encounter
More than 60 health plans sell data to at least one data broker. This accounts for about **60%** of all US medical claims transactions.⁴

2 SECONDARY DATA SOURCES



THE EHR COMPANY

Electronic Health Record (EHR) companies have access to and sometimes ownership of the data in their EHRS.¹³
Many will de-identify and sell my healthcare data. The Practice Fusion model was one of the first to sell data to pharma and advertise drugs directly to providers.

PHARMACY BENEFIT MANAGERS

PBMs collect pharmacy data from claims.
They sell data to pharma companies who are interested to learn where their drugs are doing well vs poorly. **85%** of PBMs sell to ExamOne who sells 7 years of an individual's prescription history to life and health insurers.¹³

MY BANK

Throughout the process, my bank tracks copays with my doctors office and pharmacy. It also has record of my monthly premiums with my insurer.
Many banks sell customer data.

3 GROUPS WITH ACCESS

HEALTH IT MIDDLE-MEN

Health IT middle men offer services such as data warehousing, analytics, performance management solutions, claims processing, transition support to value-based payment models, and revenue optimization. They are used by provider groups, pharmacies, insurers, and more.
What PHI or de-identified health information they have access to and sell has not been measured to date. The total number of middlemen companies who can access, use, and/or sell my data is unknown.

Examples of Health IT middle men who work with health data:



THE GOVERNMENT

Federal and State health departments maintain Public Use Files (PUF), de-identified and limited datasets to support researchers (ex: utilization and spending data aggregated at the prescriber, drug name, and generic name levels).²

Federal or State data sets with Patient Health Information (PHI) can be accessed through IRB approval or other application approach.

4 DATA BROKERS

DATA MINERS

Data miners use de-identified data including longitudinal records that track my longterm health and switch my name for a number. Data comes from my medical organization, pharmacy, insurance company, federal and state health department data, and more.⁵
Even de-identified, this data can provide valuable, population health insights and demographic profiling for individuals.

DATA BROKERS

Data brokers sell identified profiles. In 2014, the FTC reported that Axiom had "over 3,000 data segments for nearly every U.S. consumer."⁷

Data brokers gather health data and health related digital footprint data, such as health related purchases, consumer genetic testing, and apps. EliteMate, a dating service, sells a list of individuals and their mailing addresses with AIDS/HIV.^{10, 13}



5 DATA USERS

CLINICAL RESEARCH

Research Centers
Researchers use many data sources including Federal and State data sets, clinical study reports, and more. Some data brokers will give research centers a discount on population health data.¹¹

MARKET ANALYSIS AND TARGETED ADVERTISING

Pharmaceutical companies
Population health data can help pharma companies determine which drugs to develop or invest in. Data inform Pharma where certain drugs are doing poorly and need more marketing. Profiles on doctors prescribing practices lead pharma companies to target certain providers to increase sales.¹³ Pharma can also cross-reference de-identified and identified records from Miners and Brokers in order to learn more about individual customers.

Marketers
Marketers use health data to target consumers. For example, marketers have purchased "sick lists" of people presumed to have a certain ailment from Axiom.⁶

Digital Advertising (Facebook, Google, Amazon, etc)
Most have their own sources of data but are interested in purchasing health data. In Feb of 2019, Facebook was caught matching ovulation health data from an app called Flo to their own users presumably for targeted advertising.⁹

RISK PROFILING

EHRs, Hospitals, and Physician Groups
It is often harder for doctors to get data about their patients from within the health system than from the outside. Re-identified data can flesh out a patient's record. Population data can predict patient risk. Some data brokers include "criminal records, online purchasing histories, retail loyalty programs and voter registration data" in their reports.⁸

Health Insurance
The ACA denies health insurers to exclude patients with pre-existing conditions. However, payers are interested in getting risk scores for their patient populations to manage populations, determine an individual's premium charges, and even deny coverage.^{1, 13}

Car Insurance, House Insurance, Life Insurance, Job application, Cell phone or utility company
When assessing customers' financial risk, insurers and even employers may purchase health risk profiles.

SCENARIO

At an appointment with my doctor, who...
1. reviews my blood test results
2. diagnoses IBS, and
3. prescribes Bentyl

HIPAA AND MY MEDICAL RECORD

Medical records can contain history of my health events including hospitalizations, diagnoses, medication lists, family history. In 1996, HIPAA ruled that medical record data could be shared if it was de-identified by removing name and a few other personally identifying data.

MY DIGITAL FOOTPRINT

Social media companies, banks, apps on your phone, browser trackers, and other companies that have access to your digital foot print sell your data. HIPAA doesn't regulate this data even though it can paint a vivid picture of your health. The data may also be used to re-identify de-identified healthcare data.¹²

Q Is it difficult to re-identify data?

Researchers have long demonstrated that it is not difficult to re-identify de-identified data.¹⁰ One study found that "63% of the population can be uniquely identified by the combination of their gender, date of birth, and zip code alone."⁹

SOURCES

¹ Avila, J., & Marshall, S. (2012, September 13). Your Medical Records May Not Be Private: ABC News Investigation. Retrieved May 2, 2019, from <https://abcnews.go.com/Health/medical-records-private-abc-news-investigation/story?id=17228986>

² Doshi, J. A., Hendrick, F. B., Graff, J. S., & Stuart, B. C. (2016). Data, Data Everywhere, But Access Remains a Big Issue for Researchers: A Review of Access Policies for Publicly-Funded Patient-level Health Care Data in the United States. EGEMs (Generating Evidence & Methods to Improve Patient Outcomes), 4(2), 8. doi:10.13063/2327-9214.1204

³ Golle, P. (2006). Revisiting the uniqueness of simple demographics in the US population. Proceedings of the 5th ACM Workshop on Privacy in Electronic Society - WPES 06. doi:10.1145/1179601.1179615

⁴ Health Care Data Management & Data Linking - LexisNexis. (2016, October 31). Retrieved May 2, 2019, from <https://perma.cc/LL7V-BWXR>
This is a Perma.cc record.

⁵ Leetaru, K. (2018, April 02). How Data Brokers And Pharmacies Commercialize Our Medical Data. Retrieved May 2, 2019, from <https://www.forbes.com/sites/kalevleetaru/2018/04/02/how-data-brokers-and-pharmacies-commercialize-our-medical-data/#71c8e52911a6>

⁶ Pettypiece, S., & Robertson, J. (2014, September 11). Sick Elderly for Sale by Data Miners for 15 Cents a Name. Retrieved May 2, 2019, from <https://www.bloomberg.com/news/articles/2014-09-11/how-big-data-peers-inside-your-medicine-chest>

⁷ Ramirez, E., Brill, J., Ohlhausen, M. K., Wright, J. D., & McSweeney, T. (n.d.). Data brokers: A call for transparency and accountability (United States, Federal Trade Commission). Found at <https://www.ftc.gov/system/files/documents/reports/data-brokers-call-transparency-accountability-report-federal-trade-commission-may-2014/140527databrokerreport.pdf>

⁸ Ravindranath, M. (2018, October 30). Does your doctor need to know what you buy on Amazon? Retrieved May 2, 2019, from <https://www.politico.com/story/2018/10/30/the-doctor-will-see-through-you-now-893437>

⁹ Statt, N. (2019, February 22). App makers are sharing sensitive personal information with Facebook but not telling users. Retrieved May 2, 2019, from <https://www.theverge.com/2019/2/22/18236398/facebook-mobile-apps-data-sharing-ads-health-fitness-privacy-violation>

¹⁰ STD.DATERS.COM - AIDS/HIV MEMBERS POSTAL & EMAIL Mailing List. (n.d.). Retrieved from <https://perma.cc/6LPR-V6FH>
This is a Perma.cc record.

¹¹ Tanner, A. (2016, February 01). How Data Brokers Make Money Off Your Medical Records. Retrieved May 2, 2019, from <https://www.scientificamerican.com/article/how-data-brokers-make-money-off-your-medical-records/>

¹² Tanner, A. (2017, March 02). Strengthening Protection of Patient Medical Data. Retrieved May 2, 2019, from <https://tcf.org/content/report/strengthening-protection-patient-medical-data/?agreed=1>

¹³ Tanner, A. (2018). Our Bodies, Our Data: How Companies Make Billions Selling our Medical Records. Boston, MA: Beacon Press.