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# Fact Sheet

*The Prescription Project promotes appropriate prescribing, free of conflicts of interest caused by pharmaceutical marketing and based on the best available medical evidence.*

*It is promoting policy change by working with*

- *State and Federal Policymakers*
- *Academic Medical Centers*
- *Professional Medical Societies*
- *Private Payers*

*Created with The Pew Charitable Trusts, the Project is led by Community Catalyst in partnership with the Institute on Medicine as a Profession.*

## Data Mining & Medicaid

### What is data mining?

Pharmaceutical companies buy doctors' prescribing records and use the information to target their marketing to physicians. (The pharmaceutical industry buys this information from companies known as "health information organizations," which purchase the records from pharmacies, merging these data with a list of prescriber identification numbers purchased from the American Medical Association.) The result is a detailed prescribing history for every individual doctor.)

This practice negatively affects:

- **Public Health:** Marketing based on prescriber data often involves biased and inaccurate information about health risks, and encourages the prescribing of new drugs that might be riskier to patients than already established treatments.
- **Cost:** Marketing based on prescriber data is a key factor in the skyrocketing costs of prescription drugs and the increased usage of expensive brand-name medicines.
- **Privacy:** Sales of prescriber data take place without the consent, and generally without the knowledge, of physicians. Patient records may also be inadequately protected, particularly in small communities with few physicians or few patients with particular diagnoses.

### Can Medicaid data be sold?

- **Not by the state Medicaid agency or companies contracting with Medicaid.**
- Most Medicaid data may not be sold – or even given away - by a *state's* Medicaid agency without violating federal law.<sup>1</sup> The data may be used for the administration of the Medicaid program, however, and may be shared for this purpose with private companies.<sup>2</sup> The state agency is required to ensure that the private companies who are given this data follow the use and disclosure restrictions required by federal law.<sup>3</sup>

<sup>1</sup> See generally, 42 Code of Federal Regulations, Part 461.

<sup>2</sup> 42 CFR 431.300, 431.303

<sup>3</sup> 42 CFR 431.306(b)

**State of Hypothetica: A Cautionary Tale**

The state of Hypothetica's Medicaid agency contracted with a company to audit whether the program was receiving all the price rebates it had negotiated with pharmaceutical companies. The company provided this as a free service, so the agency did not use its usual contract. The agreement provided by the company did not include a requirement to adhere to the federal use and disclosure restrictions for Medicaid data. The company removed patient names and addresses, but sold information about patients' health conditions and prescription histories to health information companies. In this case, the *agency* was in violation of Medicaid rules and faced potential federal sanctions.

- Some Medicaid data is available from the *federal* agency, the Centers on Medicare and Medicaid Services (CMS), for certain purposes or uses.<sup>4</sup>
- If a physician prescribes a drug for a patient with Medicaid coverage, and the pharmacy sells that record (stripped of patient information), that sale is not covered by federal Medicaid law and is legal. Only New Hampshire, Maine, and Vermont have passed laws to regulate the sale or transfer of prescription data for marketing purposes. These laws are currently being challenged in court. More information is available at the Prescription Project website: [www.PrescriptionProject.org](http://www.PrescriptionProject.org)

**Don't researchers use Medicaid data?**

- **Yes.**
- Some Medicaid data is available from the *federal* agency (CMS) for research (and other) purposes.<sup>5</sup>
- When requesting CMS data that includes information that can be used to identify an individual (directly or indirectly by combining it with other data), researchers must sign an extensive agreement limiting the use, re-use, and disclosure of the data to the specific purpose outlined in the agreement. Violation of this agreement is a criminal penalty.<sup>6</sup>

**How is Medicaid data protected?**

- The state agency is responsible for protecting Medicaid data.
- If Medicaid data is provided to a private company that is working with the agency, the agency must ensure the company understands that the data is confidential and may not be used or sold to others.<sup>7</sup> The state can do this by including a provision in the contract or agreement it makes with company.

<sup>4</sup> See generally 42 CFR Part 461. CMS provides Medicaid data in several forms, and does provide data that contains patient and provider level information upon request for *specified* uses, including research. For more information on Medicaid data sources and availability, see the CMS website: <http://www.cms.hhs.gov/MedicaidDataSourcesGenInfo/>

<sup>5</sup> For information about what data is available for research, see the Research Data Assistance Center's website: <http://www.resdac.umn.edu/Medicaid/index.asp>

<sup>6</sup> See the CMS website: <http://www.cms.hhs.gov/cmsforms/downloads/cms-r-0235.pdf>

<sup>7</sup> 42 CFR 431.306(b)

**What can state policymakers do to ensure Medicaid data is protected?**

State Medicaid directors, governors, and state legislators can:

- Enact a state law providing a penalty for violations of Medicaid confidentiality. Federal regulations require each state to have a state law providing for enforcement of the confidentiality and use restrictions.<sup>8</sup>
- Ensure Medicaid contracts, or other agreements, include a legally binding provision requiring the private entity to maintain the standards required under federal law.

For more information on data mining and the complete toolkit, visit the Prescription Policy website at: [www.PrescriptionProject.org](http://www.PrescriptionProject.org).

For more information on Medicaid confidentiality, see the NLRx Policy Brief “State Medicaid Data: Legal Issues Concerning Use and Disclosure” available at: <http://www.reducedrugprices.org/read.asp?news=1594>

This fact sheet was prepared for the Prescription Project by Robin Lunge, Policy Director of the National Legislative Association on Prescription Drug

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<sup>8</sup> 42 CFR 431.301 provides that “A State plan must provide, under a State statute that imposes legal sanctions, safeguards meeting the requirements of this subpart that restrict the use or disclosure of information concerning applicants and recipients to purposes directly connected with the administration of the plan.”