

Dear Ms. Alman:

Thank you for your letter regarding improving health care quality for consumers and Oregon's Health Insurance Premium Rate Review Grant Cycle IV. I appreciate the concern you expressed about protecting the privacy of consumers and assuring that organizations charged with collecting and analyzing health care data are free of conflicts of interest. Among my team at the Center for Consumer Information and Insurance Oversight (CCIIO) and across the Centers for Medicare and Medicaid Services (CMS) and Department of Health and Human Services (HHS), protecting the privacy of sensitive health information and data is of paramount importance.

CCIIO's State Exchange Group (SEG) is responsible for carefully reviewing each grant application and conducting oversight to ensure that the provisions and requirements of the grant are met. The Oregon Department of Consumer and Business Services, Insurance Division's Cycle IV application was no exception. CCIIO, HHS and CMS recognize the importance of effective grant management and oversight to ensure that every aspect of our mission is carried out in a cost-effective and responsible manner. We appreciate your concern about conflicts of interest among entities engaged by the state of Oregon to serve as their data center; however, the "Q-Corp" (Oregon Health Care Quality Corporation) is a trusted source of data and analytics on the quality and utilization of health care in Oregon. In addition, the Q-Corp is one of the first entities to be certified for Medicare data sharing and recently issued the first public report on provider performance and cost under the Medicare [Data Sharing for Performance Measurement Program](#). As such, I am confident that the Q-Corp has been thoroughly vetted.

The HIPAA Privacy Rule provides federal protections for individually identifiable health information held by covered entities and their business associates, and gives patients an array of rights with respect to that information. HIPAA specifies a series of administrative, physical, and technical safeguards for covered entities and their business associates to assure the confidentiality, integrity, and availability of electronic protected health information. Although HIPAA does not specifically refer to all-payer-all-claims (APAC) databases, to the extent permitted under federal and state law, consumers could be allowed to review their claims data if the Oregon APAC system is designed to securely identify and share an individual's claims data on request. In addition, as I'm sure you know, states implementing APAC reporting systems may also have developed their own protections to balance privacy and confidentiality of sensitive health care data with data management controls and privacy practices to ensure the integrity of the data.

Thank you for your comments and interest in enrollments in Marketplace coverage. Please do not hesitate to contact me if you have any further thoughts or concerns.

*Sandy Habit  
Policy Coordinator  
Center for Consumer Information and Insurance Oversight*

Dear Ms. Habit and Dr. Cohen,

I respectfully disagree with your conclusion.

I have already pointed out that Oregon has both a state-run APAC and one run by Q Corp, **a nonprofit recognized by the CMS data sharing program as one of the first three Qualified Entities in the country.**

But Q-Corp is window dressing for Milliman Inc., the **for-profit** actuarial company that stores and performs analytics on Oregonians' personal health information.

I had also pointed out that:

- Milliman is one of the top purchasers of medical records.
- In 2008, the FTC found that Milliman violated the Fair Credit Reporting Act for unfair practices. Before Obamacare (when preexisting conditions could exclude an individual from being able to purchase insurance), Milliman purchased data from pharmacy benefit managers. This electronic data, gathered without consumers' knowledge, was re-purposed and marketed as "pharmacy risk scores" using IntelliScript® software Milliman developed. Insurance companies used these risk scores to make coverage decisions; higher scores meant higher medical costs for patients.

So it seems to me that you didn't dig very deeply when considering whether Oregon should qualify for federal grants--the most recent in September of 2014. <http://www.cms.gov/ccio/Resources/Rate-Review-Grants/or.html>

Section 2794(c)(1)(C) of the Public Health Service Act requires that "Data Centers **must be located at academic or other non-profit institutions.**" In addition, "a center established under subsection (c)(1)(C) shall adopt by-laws that ensures that the center (and all members of the governing board of the center) is independent and free from all conflicts of interest. Such by-laws shall ensure that the center is not controlled or influenced by, and does not have any corporate relation to, any individual or entity that may make or receive payments for health care services based on the center's analysis of health care costs." [http://legcounsel.house.gov/Comps/PHSA\\_CMD.pdf](http://legcounsel.house.gov/Comps/PHSA_CMD.pdf) pp.1494,1495

I assume these provisions are meant to eliminate conflicts of interest.

Perhaps all (or most) of the All Payer Claims databases in the U.S. are set up this way. Create a non-profit as a front for a for-profit data mining company???

It is certainly true in Colorado, which uploads personal health information to 3M Corporation. The nonprofit Center for Improving Health Care, CIVHC, is funded solely through [private foundations](#). From their [2012 990](#), CIVHC paid Treo Solutions \$1,562,500 in 2012 for software and portal development. 3M acquired Treo Solutions in April 2014.

The data that is never transparent is the true cost of care. Steven Brill will probably undergo more hospitalizations and never comprehend his insurance bills. Nor see prices come down... <http://www.npr.org/blogs/health/2015/01/05/375024427/americas-bitter-pill-makes-case-for-why-health-care-law-wont-work>

In the meantime, "nonprofit" hospitals create debtors prisons for people who can't pay their bill. <https://www.propublica.org/podcast/item/podcast-when-medical-debts-become-an-impossible-burden/>

And lobbyists for big health data, insurance companies and hospitals will make sure that continues to happen--as I have witnessed at Oregon's All Payer All Claims technical advisory group. Price negotiations are trade secrets!!!

CCIIO will undoubtedly continue to funnel more federal dollars for the "triple aim." Better health, better care, lower costs and transparent data... because there are triple aim metrics! <http://civhc.org/Resources/Triple-Aim-Resources/Colorado-Triple-Aim-Metrics.aspx/>

Not going to happen...

The Information Technology and Innovation Foundation (ITIF) encourages states to data mine sensitive data to "encourage competition between vendors focused on delivering the best analytical capabilities." <http://www.govtech.com/data/Data-Driven-Innovation.html>

HIPAA is nearly dead on arrival. Just like Mark Chanko who had the misfortune to die in the NewYork-Presbyterian Hospital Emergency Room before he could tell Dr. Mehmet Oz he didn't want his death broadcast on network TV. <https://www.propublica.org/article/when-a-patients-death-is-broadcast-without-permission>

And we just worry about the NSA???

