

8/4/15

U.S. Department of Health and Human Services, Region 10
Linda Yuu Connor, Regional Manager
Office for Civil Rights
U.S. Department of Health and Human Services
701 Fifth Avenue, Suite 1600, MS - 11
Seattle, WA 98104

Dear Ms. Yuu,

Consolidation of health care information is a topic that *should* be as important as the consolidation of insurance companies and hospitals. Health data consolidation gives rise to information inequality and profits over people. Through pricing mechanisms, unknown to both the doctor and patient, access to care erodes.

Disclosing “protected” health information (PHI) without consent is an oxymoron. Protecting privacy¹ is “a clear example of an ethical obligation that must span the entire health care system.” The AMA’s principles of medical ethics² require the physician to “safeguard patient confidences and privacy within the constraints of the law.” But the physician should “also recognize a responsibility to seek changes in those requirements which are contrary to the best interests of the patient.”

That’s why I am sending this letter of complaint, which is directed toward the following:

- The **Department of Health and Human Services** for amendments to the HIPAA Privacy Rule that weaken privacy protections through exempting clearinghouses from HIPAA privacy rules for “operations” and consequentially discriminate against those who seek confidentiality, but cannot self-pay.
- The **Oregon Health Authority (OHA)** for choosing Milliman Inc. to warehouse Oregon’s All Payer All Claims (APAC) database; and for refusing my request to review my protected health information and metadata contained in the APAC.
- **Kaiser Permanente** for not giving notice and requiring consent for disclosures of my protected health information to the Oregon Health Care Quality Corporation³ (Q Corp).
- The **Center for Consumer Information and Insurance Oversight (CCIIO)** for awarding federal grants to the Oregon Insurance Division, despite Section 2794 provisions of the Public Health Service Act.

¹ <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/the-ethical-force-program/privacy-confidentiality/consensus-report.page?>

² <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/principles-medical-ethics.page>

³ <http://Q Corp.org/>

Our household was affected by two of this year's biggest data breaches, and I don't trust *any* data, in motion or at rest, to be secure. My husband, who works as a Kaiser radiologist in Portland Oregon, was notified his data was in the Premera breach for unclear reasons. While I left my career as an endocrinologist in the late 1990s, I received a letter from the U.S. Office of Personnel Management (OPM)—presumably for my stint as an Albuquerque VA internist from 1987-89.

More ominously my husband and I experienced tax related-identity theft. Tax ID theft is not inconsequential, both for the individual, the U.S. Treasury and State Departments of Revenue.

Clearly, the OPM's security is flawed. But the OPM's "fair practices in all aspects of personnel management"⁴ obviously do not include "fair information practice principles"⁵ since my data is over 25 years old. *Current* federal employees have much more to worry about than me. Because of significant breaches in at least three databanks⁶ the OPM manages, investigators are probing all of its databases—including a controversial health claims data warehouse.⁷

Since 2002, health records are open to "routine use" by the OPM and "millions of providers, employers, government agencies, insurance companies, billing firms, transcription services, pharmacy benefit managers, pharmaceutical companies, data miners, creditors and more". That's when the "right of consent" replaced the HIPAA "Privacy rule" with "*regulatory permission for covered entities to use and disclose protected health information for treatment, payment, or health care operations.*"⁸

James Pyles, an attorney who specializes in health information technology and health information privacy says, CMS and HHS have conceded that electronic health records just "can't be made secure."⁹ With massive data breaches, victims never know to what extent their information was compromised, how widely it was distributed or whether their health records were contaminated because Electronic Health Records can exist in an infinite number of locations.

Mergers in the health care industry exacerbate the problem. If Anthem's proposed purchase of Cigna survives anti-trust scrutiny, it may become the biggest giant among just three commercial

⁴ <https://www.opm.gov/about-us/>

⁵ <http://www.nist.gov/nstic/NSTIC-FIPPs.pdf> *Data Minimization: Organizations should only collect PII that is directly relevant and necessary to accomplish the specified purpose(s) and only retain PII for as long as is necessary to fulfill the specified purpose(s).*

⁶ <http://www.nextgov.com/cybersecurity/2015/07/opm-changes-privacy-rules-let-investigators-inside-all-databases/118105/>

⁷ <http://www.gpo.gov/fdsys/pkg/FR-2011-06-15/pdf/2011-14840.pdf> ;

<http://www.computerworld.com/article/2513890/data-privacy/privacy-advocates-fear-massive-fed-health-database.html> The data that the agency collects will include individuals' names, addresses, Social Security numbers and dates of birth, plus the names of their spouses and other information about dependents, and information about their healthcare coverage, procedures and diagnoses.

⁸ <https://patientprivacyrights.org/truth-hipaa/>

⁹ http://pow.gbdev1.com/uploads/29/doc/Wash_Internet_Daily_Mar_2015.PDF

health insurance giants.¹⁰ Instead of a data breach affecting 80 million current and former customers, a future Anthem breach could exceed 100 million.¹¹

Given these risks, HHS must re-examine the HIPAA Privacy Rule, especially as it pertains to data released without consent for “operations.” “Operations” are a broadly defined category that includes fund-raisers and third party clearinghouses that act as data warehouses.¹²

The Clearinghouse Rules: profits over people

Health care operations” are “compatible with and directly related to... treatment and payment and for which protected health information could be used or disclosed without individual authorization.”¹³ Calculations of drug costs, discounts, or copayments are health care operations if performed in the aggregate for a group of individuals. Quality assessment and improvement activities also count as health care operations.

The Oregon Health Authority cited a 2000 HIPAA privacy rule in their refusal to allow me to review my APAC data.¹⁴ PHI incorporated into information systems used for quality control or peer review analyses is not considered a “designated record” utilized for making decisions about individuals. The OHA states “benefits of access to information not used to make decisions about individuals is limited and is outweighed by the burdens on covered entities of locating, retrieving, and providing access to such information.”

HHS maintains “the exemption for health care clearinghouses from certain provisions of the regulation dealing with the notice of information practices and patient's direct access rights to inspect, copy and amend records on the grounds that a *health care clearinghouse is engaged in business-to-business operations, and is not dealing directly with individuals.*¹⁵

Kaiser Permanente’s Notice of Privacy Practices states, the right to an accounting of disclosure of PHI “does not include certain disclosures to carry out treatment, payment and health care operations.” Kaiser Permanente cited Section 164.522 of the HIPAA privacy rule¹⁶ in their

¹⁰ <http://money.cnn.com/2015/07/24/news/companies/anthem-cigna-merger/index.html>

¹¹ <http://www.nytimes.com/2015/02/05/business/hackers-breached-data-of-millions-insurer-says.html>

¹² <http://www.theofrancis.com/article/spread-records-stirs-patient-fears-privacy-erosion>
<http://www.hhs.gov/ocr/privacy/hipaa/understanding/coveredentities/usesanddisclosuresfor tpo.html>

¹³ <https://www.federalregister.gov/articles/2000/12/28/00-32678/standards-for-privacy-of-individually-identifiable-health-information>

¹⁴ <https://www.federalregister.gov/articles/2000/12/28/00-32678/standards-for-privacy-of-individually-identifiable-health-information>

¹⁵ Final Privacy Rule Preamble -- Discussion of Comments §§ 164.524 and 164.526,
<http://aspe.hhs.gov/admsimp/final/PvcPre03.htm>

¹⁶ <https://www.law.cornell.edu/cfr/text/45/164.522> (v) A restriction agreed to by a covered entity under paragraph (a) of this section, is not effective under this subpart to prevent uses or disclosures permitted or required under § 164.502(a)(2)(ii), § 164.510(a) or § 164.512. (vi) A covered entity must agree to the request of an individual to restrict disclosure of protected

refusal. (Q Corp’s “Compare Your Care”¹⁷ link is useless when it comes to making “informed” decisions about one’s health care.) While there is no legal requirement for the disclosure to this reporting program, which began in 2008,¹⁸ Kaiser can argue that I had not fully paid for services for which data was disclosed without my consent.

The HIPAA privacy rule¹⁹ states “business associates of plans and providers, health care clearinghouses are bound by the notices of information practices of the covered entities with whom they contract.” Health plans need only claim the clearinghouse’s work is necessary for operations to exempt them from HIPAA privacy regulations.

It’s impossible to put a price on privacy since health care data is a currency with highly variable financial value.²⁰ When clearinghouses that measure cost and quality escape notice and are exempt from scrutiny, they’re dangerous—like a closed circuit without breakers. Just as we need large switchgears as circuit breakers to protect cities and small devices to protect individual household appliances, we need data breakers of varying sizes. Giving people access to review their personal data in APACs would put breaks on the inflow of data, which is especially valuable if the data is incorrect. Without breakers in health care data, currency will flow in one direction, putting profits before people.

Clearinghouse exemptions that limit accounting disclosures and patient access are unfair and will lead to inaccurate conclusions.

- **Privacy for the rich discriminates**
- **Garbage in. Garbage out.**

Privacy for the rich discriminates

Only the very wealthiest who self-pay for their health care have the ability to restrict disclosure of their protected health information.

U.S. Trust, the private wealth management arm of Bank of America, developed guides to help “clients and their children or heirs protect the value of their digital assets, online reputation,

health information about the individual to a health plan if: (A) The disclosure is for the purpose of carrying out payment or health care operations and is not otherwise required by law; and (B) The protected health information pertains solely to a health care item or service for which the individual, or person other than the health plan on behalf of the individual, has paid the covered entity in full.

¹⁷ <http://www.q-corp.org/compare-your-care>

¹⁸ Contract Number 133760 between Milliman Incorporated and the Office for Oregon Health Policy and Research (OHP) Q Corp is a “voluntary program involving both private and public payers.” <http://tiny.cc/z87txx>

<https://olis.leg.state.or.us/liz/2015R1/Downloads/CommitteeMeetingDocument/56344>

¹⁹ Final Privacy Rule Preamble -- Discussion of Comments

<http://aspe.hhs.gov/admsimp/final/PvcPre03.htm>

²⁰ <http://www.npr.org/sections/monkeysee/2013/06/09/189857722/when-your-data-is-your-currency-what-does-your-privacy-cost>

privacy and security.” Protecting digital assets means “ownership of and access to social media sites, photos, health records, loyalty programs, business intelligence and other confidential information.”²¹

Rapidly expanding and interconnected health data raise the risk of adverse impacts arising from discrimination.²² Job discrimination is the most common complaint sent in to Patient Privacy Rights.²³

The only way to “own” health records and restrict disclosures to a health plan concerning treatment is to self-pay²⁴... and preferably with untraceable cash. Databases that link payment with a credit or debit card to a customer discount card for drugs (e.g. birth control, antidepressants and HIV drugs) can undermine confidentiality.²⁵

Garbage in Garbage Out

While a clearinghouse may not have direct contact with individuals, they have individually identifiable health information “that may be subject to misuse or inappropriate disclosure”—comments acknowledged by HHS in rule making.²⁶

In Oregon, only covered entities can correct APAC reporting errors. Could data be manipulated to minimize true out-of-pocket costs that patients incur and maximize medical loss ratios?

The misuse of data is not apparent when “correct” data doesn’t include outliers. The most important outliers are patients who cannot afford appropriate and necessary inpatient and outpatient care—measurements that are an embarrassing statistic for arguably the wealthiest developed country.

- 35 million uninsured Americans²⁷ are outliers for measurements of quality and safety don’t apply.
 - Millions of *under-insured* Americans, whose out-of-pocket expenses are cost-prohibitive, are also outliers for the same reason.
 - The woman with a known benign breast mass whose pre-existing abnormality disallows a “free” preventive mammogram. The woman with “dense breasts” on

²¹ <http://newsroom.bankofamerica.com/press-releases/us-trust/managing-wealth-includes-online-reputation-and-digital-asset-management-us-t>

²² <http://www.theatlantic.com/health/archive/2012/08/protecting-our-civil-rights-in-the-era-of-digital-health/260343/>

²³ <https://patientprivacyrights.org/your-health-privacy-rights/>

²⁴ § 164.522(a)(1)(vi) <https://www.law.cornell.edu/cfr/text/45/164.522>; Final Privacy Rule Preamble -- Discussion of Comments <http://aspe.hhs.gov/admnsimp/final/PvcPre03.htm>

²⁵ <http://www.theatlantic.com/health/archive/2012/08/protecting-our-civil-rights-in-the-era-of-digital-health/260343/>

²⁶ Final Privacy Rule Preamble -- Discussion of Comments <http://aspe.hhs.gov/admnsimp/final/PvcPre03.htm>

²⁷ <http://harpers.org/archive/2015/07/wrong-prescription/2/>

- mammogram who can't pay for additional studies since those studies are diagnostic and no longer "free."²⁸
- The patient with ulcerative colitis whose pre-existing penalty carries diagnostic costs with a higher risk of colon cancer.²⁹

A perverse aspect of Obamacare arises when a patient must pay for premiums, but is too poor to pay for the actual care.

Other outliers will be smoothed by statistics. Surgeons will tend to cherry pick patients and avoid patients that are too "high risk"³⁰ to improve reporting grades. When surgery is recommended for sicker patients with good insurance, sufficient numbers of cherry picked healthier patients can mitigate bad outcomes and there is less financial risk for the hospital and provider.

Value in big data: For whom?

Trudy Lieberman, a Harpers journalist, says a "Great Cost Shift" replaces the crisis of uninsurance with underinsurance.³¹ Indeed, America's patchwork delivery system will become even more inequitable as cost shifts will surely escalate with market consolidation. Doctors' salaries are likely to drop as more become salaried, but premiums and/or cost-sharing will likely rise too.³² Industry consolidation does not bode well for the doctor-patient relationship.

*The value of some data is increased by hiding it or making it inaccessible.*³³ This is certainly true of health care prices. Health care "accountability" doesn't account for the high price of compromised privacy and confidentiality when "protected" health information is mined without our consent.

When industry giants hoard data, they have a tighter rein on the market. Never mind the so-called "market" has no health care price stickers. Without price caps or price transparency, industry stakeholders can mask cost shifting buried in "affordable" premiums mandated by the Affordable Care Act.

²⁸ http://well.blogs.nytimes.com/2014/06/16/dense-breasts-may-obs-cure-mammogram-results/?_r=0

²⁹ <http://healthinsurance.bangordailynews.com/2014/03/18/when-insurers-say-no/affordable-care-act-not-all-colonoscopy-are-preventive/>

³⁰ http://www.nytimes.com/2015/07/22/opinion/giving-doctors-grades.html?emc=edit_th_20150722&nl=todaysheadlines&nid=67042940

³¹ <http://harpers.org/archive/2015/07/wrong-prescription/2/> a transfer of "the growing price of medical care to patients themselves through high deductibles, coinsurance (the patient's share of the cost for a specific service, calculated as a percentage), copayments (a set fee paid for a specific service), and limited provider networks (which sometimes offer so little choice that patients end up seeking out-of-network care and paying on their own)

³² <http://www.nber.org/papers/w15434>

³³ <http://www.hrexaminer.com/who-owns-data-6-data-principles/>

A 2005 study by the Rand Corporation³⁴ (paid by companies that have profited by developing and selling electronic records systems to hospitals and physician practices) predicted \$81 billion yearly savings in health care costs. Instead, health care spending rose \$800 billion in the first eight years since 2005 report was issued. This Rand study led to an explosive use of electronic health records when a 2009 stimulus bill pumped \$28 billion of HITECH incentives.

EHRs have not integrated America's fragmented health care system.³⁵ Nor have EHRs yielded savings through health care and prescription drugs cost saving. Even if purchasing health care was like shopping for a car, there's no easy way to figure out the cost of care.

Passed in 2009, HB 2009³⁶ was an omnibus bill that created Oregon's All Payer All Claims (APAC) Data Reporting Program. Oregon's APAC is intended to support "triple aim" goals³⁷ — better health, better care, and lower costs—across all markets.

Eligibility files, medical and pharmacy claims, and provider data files are collected quarterly.³⁸ Oregon's APAC³⁹ program specifically excludes uninsured and self-pay data.⁴⁰

The databases for Q Corp and the Oregon Health Authority were constructed to avoid disclosure of trade secrets.⁴¹ Insurance companies have guarded rate filings as trade secrets,⁴² claiming "disclosure would provide competitors with an unfair advantage, possibly reducing competition

³⁴ <http://www.nytimes.com/2013/01/11/business/electronic-records-systems-have-not-reduced-health-costs-report-says.html>

³⁵ Wrong Prescription? The failed promise of the Affordable Care Act
<http://harpers.org/archive/2015/07/wrong-prescription/9/>

³⁶ [https://olis.leg.state.or.us/liz/2009R1/Downloads/MeasureDocument/HB2009 p.8 Section \(2\);](https://olis.leg.state.or.us/liz/2009R1/Downloads/MeasureDocument/HB2009_p.8_Section(2);) Also see Section 1201 pp 533-535

³⁷ <http://www.oregon.gov/oha/analytics/Pages/Sustainable-Healthcare-Expenditures.aspx>;
<http://www.oregon.gov/oha/analytics/APACDocs/Charter.pdf>;

³⁸ Eligibility files capture patient demographic information such as date of birth, gender, geography, and race/ethnicity and serve as the starting point for identifying claims and providers to be included in the data submissions. Medical claims and pharmacy claims files capture plan payments, member financial responsibility (co-pay, co-insurance, deductible), diagnoses, procedures performed, and numerous other data fields. Provider data files include information on location and provider specialty. At the current time, only limited provider information is available in the limited data sets. The public use data set contains no provider information.

³⁹ http://www.oregon.gov/oha/OHPR/RSCH/docs/All_Payer_all_Claims/APAC-Overview-for-Release-Document.pdf

⁴⁰ http://www.oregon.gov/oha/OHPR/RSCH/docs/All_Payer_all_Claims/APAC-Overview-for-Release-Document.pdf Data comes from commercial health insurance carriers, licensed third party administrators, pharmacy benefit managers, Medicaid managed care organizations, Medicaid fee-for-service and Medicare parts C and D commercial health plans.

⁴¹ <http://Q.Corp.org/sites/qcorp/files/ExhD-DUPolicies-Matrix051414-CLEAN.pdf>

⁴² <http://www.nytimes.com/2011/10/12/nyregion/health-insurers-ask-to-keep-rate-increase-data-secret.html>

and raising prices even higher.” The Oregon Insurance Commissioner has proven this claim is untrue⁴³ since rate filings appear in their entirety here and the public can comment⁴⁴.

Oregon conforms to the Uniform Trade Secret Acts, where trade secret is defined as: information, including cost data, that “derives independent economic value, actual or potential, from not being generally known to the public... **and** is the subject of efforts that are reasonable under the circumstances to maintain its secrecy.”⁴⁵

Most would agree that staggering differences seen in health care prices⁴⁶ are certainly not “reasonable.” If the Oregon’s health care industry claims price negotiations have trade secret protections⁴⁷ isn’t it reasonable that individuals copyright their PHI⁴⁸ as valuable intellectual property?

APAC clearinghouses are not improving costs and quality of health care as intended. Oregon's APAC was deemed "barely useful" last year.⁴⁹

The Oregon Department of Consumer and Business Services⁵⁰ is strategically investing funds from federal grants for “actionable information” about the entire marketplace to “enhance the rate review process and in efforts to improve health care pricing transparency.” Q Corp will gain access to APAC data.

Heeding to industry lobbyists, Oregon SB 891,⁵¹ intended to improve consumer access to APAC data,⁵² failed this past legislative session.

Milliman Inc.: a clearinghouse with conflicts of interest?

Section 2794 of the Public Health Service Act requires Data Centers be located at academic or other non-profit institutions.⁵³ Presumably this section is intended to prevent conflicts of interest.

⁴³ <http://www.oregonlaws.org/ors/743.018>

⁴⁴ <http://consumersunion.org/wp-content/uploads/2014/04/Exhibit-A-State-List-Public-Participation.pdf>

⁴⁵ <http://www.oregonlaws.org/ors/646.461>

⁴⁶ http://www.huffingtonpost.com/2013/05/08/hospital-prices-cost-differences_n_3232678.html

⁴⁷ <https://www.thelundreport.org/content/hospitals-try-avoid-price-transparency-advancing-phony-bill>

⁴⁸ <http://www.hrexaminer.com/who-owns-data-3-intellectual-property/>

⁴⁹ <https://www.thelundreport.org/content/all-payer-all-claims-shows-clear-figures-medicaid>

⁵⁰ http://www.oregon.gov/DCBS/insurance/healthrates/Documents/grant/cycle_IV_project_narrative.pdf

⁵¹ <https://olis.leg.state.or.us/liz/2015R1/Downloads/MeasureDocument/SB891/Introduced>

⁵² <https://www.thelundreport.org/content/healthcare-industry-convinces-courtney-kill-pricetransparency-bill>

⁵³ <https://www.cms.gov/CCIIO/Resources/Fact-Sheets-and-FAQs/rr-foa-faq-6-6-2013.html>

Milliman Inc. won Oregon's APAC contract through a Request for Proposal (RFP) process in the summer of 2009. Milliman Inc. had a competitive edge to win the RFP.

Oregon law⁵⁴ restricts "collection of Social Security numbers and the disclosure or use of the data for any purpose other than those specifically authorized by the contract" and requires use of "unique patient and provider identifiers" to allow aggregation of patient claims across payers, including pharmacy."⁵⁵

Milliman demonstrated this, having already developed "successful patient crosswalks and single patient identifiers" for Q Corp that included data from ten data suppliers who eventually became data contributors to the APAC. Milliman⁵⁶ does this using "*proprietary methods* to unify the patient history and determine the most current information, including unifying persons with name changes, where possible."

The contract requires Milliman to identify data submissions that require correction and request resubmission from the data submitter. Milliman acknowledges **technical problems**⁵⁷ (who assigns a "unique numeric identifier" used by both health care payers and providers and how it moves throughout the system) as well as "**potential political ramifications with individuals expressing concerns about privacy.**"

The OHA APAC contract⁵⁸ with Milliman has non-disclosure stipulations against using confidential information "for any purposes whatsoever other than the provision of Services to Agency hereunder." The contract also has a clause for Competing Services.⁵⁹

⁵⁴ <https://olis.leg.state.or.us/liz/2009R1/Downloads/MeasureDocument/HB2009>

⁵⁵ Contract Number 133760 between Milliman Incorporated and the Office for Oregon Health Policy and Research (OHPR)

<https://olis.leg.state.or.us/liz/2015R1/Downloads/CommitteeMeetingDocument/56344>

<http://tiny.cc/z87txx> Contractor shall deliver a plan with the following recommendations: An algorithm for creating unique patient identifiers from data elements selected for mandatory submission.

⁵⁶ *ibid*

⁵⁷ <http://info.medinsight.milliman.com/category/apcd/page/2/>

⁵⁸ Contract Number 133760 between Milliman Incorporated and the Office for Oregon Health Policy and Research (OHPR)

<https://olis.leg.state.or.us/liz/2015R1/Downloads/CommitteeMeetingDocument/56344>

<http://tiny.cc/z87txx>

⁵⁹ *ibid* Article 6.6. p. 9. "nothing in this Contract shall preclude or limit in any way the right of Contractor to: (i) provide services similar to those contemplated in this Contract, or consulting or other services of any kind or nature whatsoever to any individual or entity as Contractor in its sole discretion deems appropriate; or (ii) develop for Contractor or for others deliverables or other materials that are competitive with those produced as a result of the Services provided hereunder, irrespective of their similarity to the Deliverables. Each party shall be free to utilize any concepts, processes, know-how, techniques, improvements or other methods it may develop during the course of performance under this Contract free of any use restriction or payment obligation to the other."

The Competing Services clause is troublesome in light of Milliman's definition of data science⁶⁰: *the intersection of the intersection of hacking skills (meaning computer programming skills to manipulate files and implement algorithms), statistics and machine learning knowledge, and subject matter expertise.* "Machine learning of big data is possible through computer rules and/or algorithms that *"automatically search through data to 'learn' how recognize patterns and make complex decisions."*

How could Oregonians ever determine whether Milliman misuses or repurposes APAC data since Milliman is also one of the top purchasers of medical records nationally⁶¹?

The All-Payer Claims Database (APCD) Council posts a list of vendors⁶² operating in the APCD "space." Only a few are academic or non-profit institutions. New Hampshire, also a recipient of a CCIIO grant,⁶³ uses Milliman for their All Claims Database.⁶⁴ A January 2015 publication⁶⁵ by the APCD Council notes data linkage is difficult and resource-intensive, even with "robust patient identifiers." Consumers are concerned about privacy and whether tools and analysis are useful and understandable. Rhode Island allows patients to opt out of their APCD.⁶⁶

The value of PHI⁶⁷ in these databases is not transparent to the health care consumer for many reasons. The value of data depends on its audience and Oregonians are certainly not the "audience" of the APAC. The health care industry stakeholders (who make up an advisory group⁶⁸) are the "audience" of the APAC. Milliman, an invaluable handmaiden to these stakeholders, sells numerous products and services⁶⁹ and surely profits as Oregon's APAC vendor.

Milliman Consulting Actuary Nancy Watkins states, "Our clients want to know who their best customers are; where they are; how likely they are to buy their products and how much profit they can expect to make off of them."⁷⁰

⁶⁰ <http://us.milliman.com/insight/2013/Why-big-data-is-a-big-deal/>

⁶¹ <http://www.bloomberg.com/infographics/2013-06-05/table-2011-medical-records-purchases.html>; <http://www.bloomberg.com/infographics/2013-06-05/whos-buying-your-medical-records.html>

⁶² http://www.apcdouncil.org/sites/apcdouncil.org/files/media/2014-11-10_apcd_council_vendor_list_final.pdf

⁶³ <https://www.cms.gov/ccio/Resources/Rate-Review-Grants/nh.html>

⁶⁴ <https://nhchis.com/>

⁶⁵ All-Payer Claims Database Development Manual: Establishing a Foundation for Health Care Transparency and Informed Decision Making; Publication date: March 4, 2015; http://apcdouncil.org/sites/apcdouncil.org/files/All-Payer%20Claims%20Database%20Development%20Manual_03042015_0.pdf

⁶⁶ <http://www.health.ri.gov/publications/memoranda/AllPayerClaimDatabaseOptOutGuidance.pdf>

⁶⁷ <http://www.hrexaminer.com/who-owns-data-6-data-principles/>

⁶⁸ <http://www.oregon.gov/oha/analytics/APACDocs/APAC-Roster.pdf>

⁶⁹ <http://www.milliman.com/productfinder/>

⁷⁰ <http://us.milliman.com/insight/videos/Predictive-analytics-Uncovering-value-in-the-data/>

That includes products like MedInsight®⁷¹ (a data warehousing and decision-support tool) and consulting services for ACA risk adjustment.⁷² The list for health care products and services is extensive.⁷³ To name a few: analytics and technology⁷⁴; benefit program design and evaluation⁷⁵; mergers and acquisitions⁷⁶ and Milliman Health Cost Guidelines.⁷⁷

Milliman's footnote on HCGs states "detailed claims and enrollment data underlying the guidelines represent over 54 million commercially insured lives, including published and unpublished data... *Since these guidelines are a proprietary document of Milliman, they are only available for release to specific clients that lease these guidelines and to Milliman consulting health actuaries.*"

Milliman is clearly not an academic or non-profit institution. Yet the Center for Consumer Information and Insurance Oversight (CCIIO) has awarded the Oregon Insurance Division 4 federal grants totaling ~\$9.8 million since 2010.

I wrote Dr. Mandy Cohen MD, MPH Principal Deputy Director of CIIIO,⁷⁸ to raise concerns about conflicts of interest that might arise. Policy Director Sandy Habit responded, and merely praised Q Corp as a "trusted source of data and analytics" without referring to Section 2794 of the Public Health Service Act as it applies to Milliman Inc.

Oregon's APAC presents conflicts of interest for Milliman and CCIIO should have acknowledged this.

Data on request

Ms. Habit also wrote: "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.*"

Milliman *can* securely identify and share an individual's claims data on request.

Mylia Christensen, Executive Director of Q Corp, fulfilled a similar request of my data in Q Corp's database. I went to Q Corp's downtown Portland office on June 12th to retrieve a flash drive from

⁷¹ <http://www.milliman.com/Solutions/Products/MedInsight/>

⁷² <http://www.milliman.com/insight/2015/ACA-risk-adjustment-Special-considerations-for-new-health-plans/>

⁷³ <http://www.milliman.com/productfinder/>

⁷⁴ <http://www.milliman.com/productfinder/?bnid=476>

⁷⁵ <http://www.milliman.com/productfinder/?bnid=171>

⁷⁶ <http://us.milliman.com/Solutions/Services/Mergers-and-Acquisitions/>

⁷⁷

http://www.milliman.com/uploadedFiles/Solutions/Products/Resources/Health_Cost_Guidelines/hcg_commercial.pdf

⁷⁸ <http://www.cms.gov/About-CMS/Leadership/cciiio/Mandy-Cohen.html>

a Milliman employee. Q Corp's Fair Information Practices and Data Use Policies⁷⁹ assure patients' access to their own PHI, "within the bounds of applicable law and technical feasibility."

Milliman's FTC violations:

Also in 2008, the FTC found that Milliman violated Section 607(d) of the Fair Credit Reporting Act.⁸⁰ Milliman marketed Intelliscript (a service that created individual medical profiles based on prescription drug histories from pharmacy benefit managers) to health and life insurance companies.⁸¹ Milliman still sells this tool.⁸²

The FTC judgment required that Milliman notify insurers that consumers denied insurance on the basis of these reports have the right to request a copy of the report and that errors be corrected.

The FTC also found Ingenix, a subsidiary of UnitedHealth Group, similarly violated the FCRA that year.⁸³ At the time, Ingenix was also embroiled in "a scheme by health insurers to defraud consumers by manipulating reimbursement rates."⁸⁴ The largest health insurance companies in the United States had been under-reimbursing their customers for out-of-network health care services with two "data benchmarking" products sold by Ingenix. As a result, Americans paid billions of dollars for health care services that their insurance should have paid.

The following year, the Office of Oversight and Investigations followed with a report⁸⁵ for the Senate Committee on Commerce, Science, and Transportation companies. The OPM noted that approximately 911,000 federal workers (almost a quarter enrolled in Federal Employees Health Benefits Programs) were among the millions of Americans affected.

An excerpt from the executive summary:

Furthermore, all of the data Ingenix used to calculate its benchmark products came from the very same health insurers that purchased Ingenix's products, forming a "closed loop" of information between Ingenix and the insurance industry. Confidentiality agreements between Ingenix and its customers prohibited the disclosure of information about the database products to patients or doctors.

Despite this "shocking lack of transparency and accuracy," there seems to be no lessons learned.

⁷⁹ <http://Q Corp.org/sites/qcorp/files/ExhD-DUPolicies-Matrix051414-CLEAN.pdf>

⁸⁰ <https://www.ftc.gov/enforcement/cases-proceedings/062-3189/milliman-inc-matter>

⁸¹ Prescription Data Used To Assess Consumers Records Aid Insurers but Prompt Privacy Concerns; Ellen Nakashima; *Washington Post*; August 4, 2008

http://www.washingtonpost.com/wp-dyn/content/article/2008/08/03/AR2008080302077_pf.html

⁸² <http://www.milliman.com/Solutions/Products/IntelliScript/>

⁸³ <https://www.ftc.gov/enforcement/cases-proceedings/062-3190/ingenix-inc-matter>

⁸⁴ <http://www.ag.ny.gov/press-release/cuomo-announces-industry-wide-investigation-health-insurers-fraudulent-reimbursement>

⁸⁵ http://www.commerce.senate.gov/public/?a=Files.Serve&File_id=3498904d-6994-4e7d-a353-159261240d54

Black box algorithms of Milliman Inc. and the holy grail

Isn't Milliman poised to do the same as Ingenix?

Milliman claim they are “finding the health care holy grail: cutting costs, not benefits” when they market benchmarking products.⁸⁶ A health care CEO, described insurance companies’ method of usual, customary and reasonable calculations⁸⁷ as “the great black box of the healthcare industry.”⁸⁸

Since Milliman is one of the top purchasers of medical records, it would be difficult (if not impossible) to ascertain whether Oregon APAC data is re-purposed to develop products and sell services to the industry to improve their bottom line.

The Oregon Insurance Division explains rate reviews must be “actuarially sound.”⁸⁹ They need to adequately cover costs without being too high, too low, or unfairly discriminatory. With a monopoly on health care data in Oregon, Milliman is integral to this process.

Milliman offers “expertise for insurance companies⁹⁰ in rate regulatory hearings. Unsurprisingly, Health Republic Insurance and other smaller insurance plans contracted Milliman for their rate filings. Many of the larger plans also utilized Milliman's 2014 Health Cost Guidelines for actuarial value and cost sharing pricing adjustments.

These pricing adjustments should be usual, customary and reasonable. But insurance law and regulations do not establish UCR fees for specific medical procedures, which are typically defined in the insurance policy—a “closed loop” of information between Milliman and the insurance industry.

Summary

Pope Francis reminds us: "Human rights are not only violated by terrorism, repression or assassination, but also by unfair economic structures that creates huge inequalities."⁹¹

The modern version of the Hippocratic Oath includes the following provisions: *I will respect the privacy of my patients, for their problems are not disclosed to me that the world may know. I will remember that I do not treat a fever chart, a cancerous growth, but a sick human being, whose*

⁸⁶ <http://www.milliman.com/Solutions/Services/Benchmarking/>

⁸⁷ <https://www.healthcare.gov/glossary/UCR-usual-customary-and-reasonable/> the amount paid for a medical service in a geographic area based on what providers in the area usually charge for the same or similar medical service

⁸⁸ The Fuzzy Math of Health Insurance, When an Insurer’s Idea of Usual, Reasonable, and Customary Comes Up Short, You’re Stuck Paying , CNNMoney (Aug. 30, 2005)http://money.cnn.com/2005/05/26/pf/insurance/usual_and_customary/

⁸⁹ <http://www.oregon.gov/DCBS/insurance/healthrates/Documents/2016-preliminary-overview.pdf>

⁹⁰ <http://www.milliman.com/Solutions/Services/Litigation-support/>

⁹¹ <http://www.theguardian.com/world/2013/mar/13/jorge-mario-bergoglio-pope-poverty>

*illness may affect the person's family and economic stability. My responsibility includes these related problems, if I am to care adequately for the sick.*⁹²

HIPAA must be revised to reinstate notice and consent when covered entities want to disclose PHI for “operations”—especially when there is no legal mandate. Without that privilege, misuse and fraudulent access to our PHI will escalate.

If industry can guard negotiated prices as trade secrets, individuals should be afforded the equivalent right to copyright and protect their PHI as valuable intellectual property.

HHS OCR should look to precedence when evaluating my request to view my records in Oregon’s APAC. State agencies collect and analyze data from students’ educational records in state longitudinal data systems that are similar to Oregon’s APAC. Parents have similarly questioned whether the Family Educational Rights and Privacy Act allow parents to view their children’s data there. Dale King affirmed this right, stating, “SEA (State Educational Agency) are also required to provide a parent or eligible student with access to those education records it maintains.”

It may not be within the purview of HHS OCR to determine whether Oregon’s federal grants should not have been awarded because of Section 2794 provisions. Please advise me if another agency, such as the HHS Office of the Inspector General, should investigate this further.

Real cost control, as it exists in most other countries, is based on the power of the government pushing back on providers, hospitals and drug companies through negotiations and/or pricing transparency.

America does neither. Frankly, if nobody in America can comprehend health care costs, we should replace what we’ve got with a single payer system and use the government’s clout to negotiate fair prices.

Respectfully,

Kris Alman M.D.

⁹² <http://www.pbs.org/wgbh/nova/body/hippocratic-oath-today.html>

Enclosures:

- HIPAA disclosure requests
- Dated certified mail recipient receipts
- Communication with Keely L. West J.D, Legal, Policy, Public Records and Rules Oregon Health Authority
- All Payer, all-claims (APAC) data reporting program: An update
- APAC Security Measures Oregon Health Authority
- Communications with Mylia Christensen, Executive Director Oregon Health Care Quality Corporation on March 13 and March 26, 2015
- Oregon Health Care Quality Corporation Patient Request for Information Form
- Oregon Healthcare Quality Reporting System; Performance Measures, May 2013-Kaiser
- Notice of Privacy Practices Kaiser Permanente Northwest Region
- Communications 5/26/15 and 7/15/15 with Kaiser Permanente
- Email from Sandy Habit, Policy Coordinator Center for Consumer Information and Insurance Oversight
- July 28, 2014 letter from Dale King, Director of Family Policy Compliance Office affirming parents' right to access children's data in state longitudinal data system
- APCD Council Vendor List