The Power of Data: Consumer Involvement and Accountability for Connecticut's All Payer Claim Database (APCD)

Report of Recommendations

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Executive Summary

The State of Connecticut is currently engaged in the development of a database that will consolidate – for the first time – data for health encounters across every provider, facility, plan, and health claim payer. The All Payer Claim Database (APCD) is the federally funded underpinning for evidence-based reforms to achieve Triple Aim goals of reducing costs, increasing quality, and improving patient experience. Access to data can influence economic and equity analysis, health systems quality and outcomes benchmarking, and consumer transparency. This is an important project of inestimable value to our state.

A research project was undertaken to identify opportunities to influence the design, development and governance of our state's APCD to maximize its usefulness specific to patient safety and health equity/disparities researchers, and consumers. Ten states have already established APCDs, and our research team sought their insights – what went well, what could have been done differently, and how stakeholders were engaged along the way. We were looking to learn from other states and to translate what we learned into recommendations for consideration in our state.

We also gathered perspectives from patient safety and health equity/disparities stakeholders in our state to gage the level of awareness and involvement in the APCD project and to determine opportunities for renewed interest and participation to secure data that could have a powerful impact on their work.

Key findings include (1) APCDs are providing consumers access to patient safety and quality reports to make informed healthcare decisions, (2) health equity/disparities researchers are working together in data, cost, and quality collaboratives, (3) NIH is funding health data research using the APCD, (4) state cost and quality councils are utilizing APCD data to regulate hospital performance and reimbursement, (5) APCDs are predominantly operating within state agencies, independent of health insurance exchanges, and (6) opportunities for engaging stakeholders to influence the design and implementation of Connecticut's APCD.

Given the APCD project is in early stages of design and development in our state, time is of the essence to ensure the ultimate usefulness of the database. The APCD initiative provides an unprecedented opportunity to standardize, collect, analyze, report, and benchmark data necessary to improve patient safety and eliminate health disparities.

We organized our findings and recommendations in four sections: APCD Governance, Patient Safety, Health Equity, and Access & Reporting.

We appreciate the generosity of the Connecticut Health Foundation for funding this research project and stand ready to influence action on the report's recommendations.

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Introduction

Our goal is to improve the quality and equity of the healthcare system in Connecticut by aiding the design, development, and usefulness of Connecticut's All Payer Claim Database (APCD) through recommendations relative to the collection, access, and reporting of data at the intersection of patient safety and health disparities.

Are patients with non-English language preference more likely to be readmitted to the hospital after surgery? Are there certain geographic areas or patient populations that run the risk of overtreatment? If we were to stratify Patient Safety Indicators (PSIs) or level of primary care delivered by race and ethnicity, what would we find? Do the race, ethnicity, and preferred language of the provider impact outcomes of patients with shared characteristics? What are the differences in access and practice patterns, treatment costs for preventable illness, deaths from surgical complications, pneumonia, and heart attack across populations? When the state's Medicaid reimbursement policy was changed to limit purchase of glucose testing strips to only designated durable medical equipment providers, did preventable emergency room visits increase in certain zip codes due to access disruption? What is the cost of health disparities to our state's economy?

These are just a few examples of patient safety- and health equity-centric questions that can be answered if the APCD is designed with public health policymakers, advocates, researchers, and consumers in mind. This is the power of data for informed decision-making by all healthcare stakeholders. The APCD initiative provides the State of Connecticut an opportunity and federal funding to standardize, collect, analyze, report, and benchmark data necessary to improve patient safety and eliminate health disparities.

Background

About the All Payer Claim Database (APCD)

The State of Connecticut is currently engaged in a federally funded development effort to establish a program with the purpose of collecting, assessing and reporting health care information relating to safety, quality, cost effectiveness, access and efficiency for all levels of health care.[1] Enabled by Public Act No. 12-166, the program is required to (1) utilize data to provide health care consumers with information regarding the cost and quality of healthcare services, and (2) make data available to state agencies, insurers, employers, health care

providers, consumers of health care services, researchers and the health insurance exchange for the purpose of review of data as it relates to health care utilization, cost and quality.[2] Responsibility for design and implementation of the APCD was granted to the Lieutenant Governor's Office of Health Reform and Innovation (OHRI). The OHRI has since been eliminated and responsibility for developing and running Connecticut's APCD has shifted to the Connecticut Health Insurance Exchange (CTHIX).

About Patient Safety

Too often, Americans do not receive the care that they need, or they receive care that causes harm.[3] Preventable medical harm is the third leading cause of death in the United States.[4] Behind each statistic there is a name, a family, a story of sorrow -- death, disability, medical bankruptcy, unemployment. But for all patients harmed by the healthcare system there is physical and emotional pain, a profound broken trust, and disbelief that while being treated they had been harmed by preventable medical errors.

About Health Equity

According to the AHRQ, our system of healthcare distributes services unevenly across populations.[5] Some Americans receive worse care than other Americans. These disparities may be due to differences in access to care, provider biases, and poor provider-patient communication or poor health literacy.[6] Racial and Ethnic minorities and poor people often face barriers to care and receive poorer quality of care when they can get it.[7] While the AHRQ reports on national trends at the intersection of patient safety and health disparities, the State of Connecticut is one of fifteen states that do not currently provide data for inclusion in this analysis.[8]

APCD Governance

I. Introduction

As with other healthcare reform initiatives supported by federal funding, states have made varying degrees of progress towards establishing APCDs. The APCD Council, a University of New Hampshire-based convener and coordinator, has guided states that have moved forward with development.[9]

II. Research Approach

We surveyed governance and operating structure, funding sources, data sources, and data fields using state APCD websites, literature on APCDs, and interviews. We conducted interviews with APCD stakeholders at three levels; first with the national APCD Council, second with states that have already established APCDs, and third within the state of CT.

We conducted interviews in order to (1) understand federal guidance on establishing an APCD, (2) learn how other states have undertaken efforts to establish APCDs, and (3) analyze and compare the State of Connecticut's plans for its APCD with other states. We believed this was necessary for contextual analysis of data access and use at the intersection of patient safety and health disparities.

At the national level
We spoke with the APCD Council, an academic support organization providing technical assistance and coordination to state APCDs. According to the APCD Council, ten states have already established APCDs (MA, MD, NH, VT, ME, TN, MN, UT, CO and KS) and five states, including Connecticut, are in the process of implementing an APCD (CT, NY, RI, VA, and WV).[10] Another seventeen states are strongly interested in developing an APCD.

At the established state APCD level
A survey of state APCDs found that (1) most are housed in state agencies, (2) most often within public health, health finance or insurance departments, and (3) most are supported with state funds. [See Comparative Analysis State APCDs, p. 36]

All ten established APCDs include commercial payer claims, and all but two include Medicaid claims as well. Half include Medicare data currently and most are planning to include it soon. One state, Maine, includes some claims data on the uninsured through collaboration with the

largest health system in the state.[11] Recent administrative changes at the Centers for Medicare and Medicaid Services (CMS) have considerably eased the process for states to access Medicare data.[12] At least five state APCDs collect information on patient race and ethnicity, but the information is often incomplete.[13] All states include medical claims, all but one includes pharmacy data, and three include dental claims. [14]

In addition to individual state APCDs, we found two consumer data resources for healthcare cost and quality based on payer claims -- The Commonwealth Fund's *WhyNotTheBest?* and FairHealth.org.

WhyNotTheBest? provides online public access to patient safety and health care quality measures based on all payer data from Medicare, Medicaid, and private insurers from sixteen states.[15] The data is reported in three segments (1) inpatient quality indicators – condition-specific mortality and utilization rates, (2) patient safety indicators – avoidable complications and adverse events, and (3) prevention quality indicators – avoidable hospital admissions.[16] Consumers in other New England states – MA, VT, and NH - are able to compare hospitals, compare regions, and view a number of reports.

FAIR Health, an independent non-profit that was created as a result of a lawsuit by the New York Attorney General against national health insurers over prices paid for out-of-network care.[17] FAIR Health's database includes fifteen billion claims dating from 2002 to the present for healthcare services delivered across the US, including Connecticut.[18] The organization is well resourced with a staff of fifty technical and analytical experts, and has demonstrated ability for securing payer data and translating that data into useable cost information for consumers in a web-based health care pricing tool[19].

States with established APCDs reported a number of challenges, including (1) prioritizing data uses, (2) constructing effective, credible governance structures, (3) integrating the technology with existing structures, (4) funding, (5) political support, (6) clear expectations about payer data submission, and (7) clear patient and payer data security.

(1) Prioritizing data uses.
Established APCDs emphasized the need to develop a process to identify and prioritize data use cases from the beginning to ensure a common understanding of uses and fairness in access to information.

(2) Constructing effective, credible governance structures.

The APCD Council and other state APCDs advised that developing a clear and credible governance structure was crucial to managing expectations about sensitive issues such as who owns the data and allowed uses. "Governance is key – there must be a deep commitment to transparency and engagement. You must be responsive to people's concerns."[20]

(3) Integrating the technology with existing structures.
Established APCDs advised that integrating data submissions with existing and planned data reporting structures and standards was key to reducing reporting burdens and ensuring accuracy.

(4) Funding.
Established APCDs are financed in a variety of ways. Financial sustainability modeling was a challenge for some; once the initial federal funding to establish the APCD is spent, on-going maintenance and administrative costs are required to continue to provide public access to data.

(6) Political support.
Established APCDs with fully funded budgets have political support that recognizes the economic, pubic health, and social value of health data transparency and evidence-based policymaking. ACA-supported payment and delivery reforms provided impetus to build political support and will for APCDs.

(7) Clear expectations about data submission with payers.
Established APCDs noted data submission challenges as a barrier, and recommended clear standards and expectations from the beginning.

At the State of Connecticut level
We conducted interviews in order to understand (1) the state regulatory framework for the APCD, (2) the structure and accountability for developing and managing the APCD, and (3) the status of APCD development and opportunity for patient safety and health equity/disparities stakeholder input.

(1) The state regulatory framework for the APCD.
The State of Connecticut's APCD initiative was launched under the guidance of the Office for Healthcare Reform and Innovation (OHRI). To implement the APCD, the state applied and was approved for $6,554,000 in federal funding for September 2012 through 2014 as part of the CT Health Insurance Exchange's (CTHIX) Level 2 grant. [21]

During the 2013 legislative session, HB-5737, *An Act Concerning the Use of Patient Health Care Information in the All-Payer Claims Database Program*, was proposed. If passed, HB-5737 would require patients be notified and allowed to "opt out" before their health encounter data is submitted to the APCD, essentially nullifying the purpose, usefulness, and federal and state investment in the APCD. Confidence in the integrity and process of protecting consumer privacy is key to a viable APCD.

(2) The structure and accountability for developing and managing the APCD.

An Advisory Group of the SustiNet Health Cabinet was convened to guide design and implementation of the APCD. The Advisory Group consists of fifteen members; a majority of which represent state agencies, and several that also serve on the CTHIX Board.

Current APCD Advisory Group Membership[22]	
Robert Aseltine, Jr.	UConn, CT Health Information Network
Benjamin Barnes	Secretary, Office of Policy & Management
Mary Ellen Breault	CT Insurance Department
Roderick Bremby	Commissioner, Dept. of Social Services
Kevin Counihan	CT Health Insurance Exchange
Kevin Lembo	State Comptroller
Matthew Katz	CT Medical Society
Thomas Leonardi	Commissioner, CT Insurance Department
Kimberly Martone	Office of Health Care Access
Jewell Mullen	Commissioner, Dept. of Public Health
Dean Myshrall	Bureau of Enterprise Systems & Technology
Patricia Rehmer	Commissioner, Dept. of Mental Health and Addiction Services
Robert Tessier	Coalition of Taft-Hartley Funds
Victoria Veltri	State Healthcare Advocate
Thomas Woodruff	Director, Health Care Policy & Benefit Services, Office of State Comptroller

Earlier this year, responsibility for the APCD initiative was transferred from OHRI to the CTHIX. The CTHIX is currently working to develop a structure to operate the APCD.[23] While both initiatives share the common characteristics of (1) emanating from the federal health reform agenda, (2) receiving federal funding for development, (3) requiring technological capacity and external vendor management, and (4) overlapping advisory group/board members, some stakeholders have raised concerns regarding the level of independence to ensure APCD data usefulness to the wider community outside of the CTHIX.

(3) The status of APCD development and opportunity for patient safety and health equity/disparities stakeholder input.

The revised published timeline for CT's APCD suggests a narrow window of opportunity for patient safety and health equity/disparities stakeholders to participate in the development of data submission guidelines, now slated for mid-May of this year. It would also appear stakeholders have an opportunity to participate in the design of consumer tools prior to October, although there are no published timelines for soliciting input from stakeholders. The timeline also suggests data will be available as soon as February, 2014, although the timeline does not indicate if the database will be available for access by public health researchers or any other stakeholder group at this time.

Revised APCD Timeline:[24]

May 1, 2013	Legal authority to collect and release data – revised legislation and regulations
May 1	Executive Director hired
May 15	**Issue Data Submission Guide**
June 1 – August 1	RFP issued
September 15	Contract signed/Data manager starts work
February 2014	**Health plans submit three years of historical data**
March	Monthly submissions begin
October	**Decision support tool available for consumers**
January 2015	Other reports for evaluation and monitoring

III. Recommendations for APCD Governance

Based on our findings, we recommend:

- An APCD governance structure be appointed separate and apart from the Health Insurance Exchange board, avoiding perceptions of conflicts of interest.

- The establishment of APCD Advisory Board sub-committee for financial sustainability.

- The APCD educate the public and policymakers to allay concerns of data privacy, misuse, commercial use, and reverse engineering of de-identified data.

- The APCD issue public report cards on quality and completeness of payer data.

- The APCD establish clear processes for data submission, access to data, and uses of data.

- The APCD provide data access to all stakeholders concurrent with CTHIX access.

- The APCD engage patient safety, health equity/disparities, and other stakeholders in meaningful collaboration to determine data collection, reporting, and access requirements in the initial design and development stage.

Using the APCD to Further Patient Safety Work

I. Introduction

Patients place their lives in the hands of health care providers every day. Yet they do so with little knowledge of the efficacy and safety of the care prescribed, the current standard of care for the treatment they seek, conflicting financial interests of the provider or facility, and safety ratings of hospitals, nursing homes and individual physicians. The lack of data transparency is an obstacle facing all health care stakeholders in making personal as well as economic healthcare decisions.

According to the Agency for Healthcare Research and Quality (AHRQ), of the ten quality measures that are worsening at the fastest pace, four relate to adverse events in health care facilities.[25] In Connecticut alone, preventable adverse events in hospitals contributed to the deaths of as many as 950 Medicare beneficiaries in 2011.[26] This statistic does not include preventable deaths for the non-Medicare population. Another 22,000 patients contracted hospital acquired infections, almost all of which were preventable.[27] Recent reports found that at least 1 in 4 patients are harmed while hospitalized.[28] Nationally, hospital acquired infections cost our economy as much as $45 billion dollars, while patient falls in 2005 alone added another $34 billion in costs.[29]

The APCD has the potential to provide data transparency for effective policymaking and at the same time provide consumers, employers, public health officials, and healthcare providers the tools to make informed choices on costs, quality, and safety.

II. Research Approach

We interviewed sixteen stakeholders who work nationally and within our state to increase transparency and accountability in the industries that are integral to our health care delivery system. We spoke with employers and consultants (Business Council of Fairfield County, Mercer, Leapfrog), unions (AFT), non-profits (Consumers Union, Center for Medical Consumers, Childbirth Connection), the National Committee for Quality Assurance (NCQA) and investigative journalists focused on healthcare issues (C-HIT).

We wanted to know (1) if stakeholders currently have access to data necessary to make informed healthcare decisions relative to patient safety and quality, (2) if not, why not, (3) how stakeholders envisioned the APCD would inform their work and decision making, and (4) if any patient safety stakeholders were currently using an APCD to inform their work.

III. Findings

Before we outline specific findings, it is important to provide context for patient safety at the national and state levels.

Patient safety stakeholders have generally not been aware of APCDs and their potential to identify patient safety problems and patterns to drive improved care. The APCD Council reported that APCDs had not been initially organized with a focus on patient outcomes, however forward thinking states like Massachusetts and Colorado are currently working on developing patient safety and quality reports. Patient safety advocates across the country have reported they are interested in our findings and recommendations to disseminate to stakeholders in their own states.

There are a number of patient safety initiatives currently underway at the national level: Joint Commission on Hospital Safety, National Quality Forum, CDC Infection initiative, and Partnership for Patients. AHRQ has designated five national priority areas: (1) Making care safer, (2) Ensuring person-and-family-centered care, (3) Promoting effective communication and care coordination, (4) Promoting effective prevention and treatment of leading causes of mortality, starting with cardiovascular disease, and (5) Working with communities to promote wide use of best practices to enable healthy living.[30]

Unfortunately, these programs have minimal consumer input. Public members (be they patients, families, caregivers, consumers) are individuals who do not have conflicting agendas; in most cases they have nothing to gain or lose professionally or financially and are the only involved parties who can be so described. They are representatives of the "public interest' rather than of personal, professional or sector interest. Transparency and accountability remain elusive and while medical consumers now at least have a seat at the table, the consumer participants have found their voice heard but not heeded.[31]

A scan of recent reporting at the state level reveals the State of Connecticut lags behind other states when it comes to hospital patient safety and quality.

(1) "Connecticut is the only New England state – and one of just three nationally – to have no hospitals designated as "Top Performers" by The Joint Commission, which issued an annual report [32] gauging the performance of more than 3,300 accredited hospitals on 45 accountability measures linked to positive patient outcomes."[33]

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(2) "Connecticut fared second-worst in the country in the percentage of hospitals hit with federal penalties for selected quality-of-care measures and in the overall rate of loss of Medicare reimbursements associated with those penalties, new federal data shows."[34]

(3) "Medicare on Thursday disclosed bonuses and penalties for nearly 3,000 hospitals as it ties almost $1 billion in payments to the quality of care provided to patients...On average, hospitals in Maine, Nebraska, South Dakota, Utah and South Carolina will fare the best, while hospitals in the District of Columbia, Connecticut, New York, Wyoming and Delaware come out among the worst, the data shows."[35]

(4) "For 2011 the number of adverse events reports (n=271) was about the same as each of the three prior years. The most common adverse events among reports were: (a) falls resulting in serious disability or death, (b) perforations during open, laparoscopic, and/or endoscopic procedures, (c) stage 3-4 pressure ulcers acquired after admission to a healthcare facility, (d) patient death or serious disability as a result of surgery, and (e) retention of foreign objects in patients after surgery. These five categories accounted for 83% of reports for events occurring in 2011." [36]

(5) Hospital acquired infections are still common in Connecticut hospitals.[37] Infections are reported separately from adverse events. Despite seven years of required reporting, only Central Line Infections in the ICU are required by law to be reported by hospitals. In coming years, more infections will be required to be reported due to federal mandates.[38] Nursing homes, ambulatory surgical centers, and dialysis centers lag behind hospitals in reporting infections.[39] Given eighty percent of all surgeries now take place outside of a hospital setting,[40] patient safety reporting must be expanded to cover all healthcare facilities, not just hospitals.

(6) One recent study looked at 377 patients at Yale-New Haven Hospital, ages 64 and older, who had been admitted with heart failure, acute coronary syndrome or pneumonia, then discharged to home. Of that group, 307 patients – or 81 percent — either experienced a provider error in their discharge medications or had no understanding of at least one intended medication change.[41]

These findings demonstrate a gap between our current and ideal experience of healthcare quality and patient safety. We have the opportunity to improve the quality of healthcare in our state, to reduce the risk to patients and the enormous costs added to the system by

preventable medical error, and to provide access to information to inform consumers about safe providers and facilities.

When we spoke with patient safety stakeholders we found (1) consistency across diverse stakeholders in the type of data they needed to make informed decisions relative to patient safety and quality, (2) the experience of barriers to data based on historic reluctance of hospitals to self-report data, lack of independently validated data, inability to benchmark and advise consumers of patient safety risks, and lack of action from regulators to demand transparency, and (3) a comprehensive menu of opportunities for APCD data use.

(1) Consistency across diverse stakeholders in both the type of data they needed and the experience of barriers to accessing data necessary to make informed decisions relative to patient safety and quality.

We found that healthcare consumers share a level of frustration of having to make healthcare decisions without the benefit of comprehensive, reliable, and independent data. This is true for both the consumer patient and the employer that foots the bill to keep its workforce healthy.

Consumers have not had access to health care data that would help them make informed healthcare choices. Only recently, and often spurred by investigative journalism in the health arena, have consumers begun to question the safety of a facility, the efficacy of a drug or medical device, or the credentials of a doctor. Consumers Union emphasizes the obvious disconnect in purchasing behavior -- while a purchaser of a car can easily access specific costs and quality ratings, the purchaser of healthcare cannot.[42]

A national consulting firm that advises employers on healthcare cost efficiency reported the frustration of not being able to more effectively advise employers on cost and quality measures in the state. Likewise, employers cannot assist their employees in making informed decisions without access to cost and quality data.[43]

The Connecticut Hospital Association advocates for its membership – hospitals. The Connecticut State Medical Society advocates for its membership – physicians. The Pharmaceutical Research and Manufacturers of America (PhRMA) advocates for its membership – pharmaceutical companies. There is no organization of similar influence and funding that cohesively advocates for Connecticut's patients. Which is why the APCD, and the data transparency it has the statutory authority to provide consumer patients, employers, advisors, researchers, and patient safety advocates is all the more important.

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Historic reluctance of hospitals to self-report data, lack of independently validated data, inability to benchmark and advise consumers of patient safety risks, and lack of action on the part of regulators to demand transparency.

Obtaining data in our own state is problematic. The inaccessibility and incompleteness of data becomes more evident when compared with other states. In Colorado and Maine, for example, hospital data is owned by the Departments of Public Health, and as a result there has been greater public access to data. Greater data transparency has informed patient safety initiatives such as the Think About It Colorado Campaign, a media blitz to the public urging research into physician and facility quality measures.[44] In Pennsylvania, an independent authority, The Pennsylvania Cost Containment Council, provides consumers access to hospital cost and quality data. The Council was formed by legislation to address rising costs and has become a consumer resource for quality measurements.[45]

In Connecticut, hospital data has not been readily accessible. Recent legislation requires some degree of transparency and public reporting; healthcare acquired infection in 2007 and hospital specific adverse events in 2008.[46] While the healthcare acquired infection legislation provided for the validation of data, the hospital specific adverse event reports are not independently validated, leaving underreporting a serious problem. [47] The Office of Inspector General found that 13.4% of Medicare beneficiaries experience an adverse event while hospitalized.[48]

The Leapfrog Group, founded by Dr. Lucian Leape, aims to inform Americans about hospital safety and quality, promote full public disclosure of hospital performance information, and help employers provide the best healthcare benefits to their workforce. [49] The Leapfrog Group's data is based on voluntary submission of hospital data. Only three hospitals in the state of Connecticut voluntarily submit data.[50]

Compounding the lack of access to independently validated data, our Department of Public Health continues to rely largely on paper, rather than electronic reporting and licensing of physicians. Until 2013, electronic relicensing was not required. This means we cannot easily ascertain how many physicians are in practice, retired, or working for an insurance or pharmaceutical company. We cannot easily quantify or accurately describe our healthcare workforce, a necessary component to evaluate access and diversity. The APCD can be used to mine and analyze physician data across all health encounters in the state.

(3) A comprehensive menu of opportunities for APCD data use.
Most often-cited all claim payer data uses included: (a) ability for consumers to make informed decisions on cost and quality, (b) ability to pinpoint outliers of overtreatment or inappropriate

treatment such as overuse of CT scans or Caesarean sections, (c) access to individual physician and facility information with optimum outcomes in specific areas such as joint replacement and back surgeries, (d) ability to find patterns of preventable medical errors and harm, (e) economic analysis of the cost of care and the cost of preventable medical error, and (f) conflicts of interests that might be driving prescribing or testing patterns.

(a) Ability for consumers to make informed decisions on cost and quality.

The medical industrial complex now comprises over 18% of our national economy.[51] Industry to consumer marketing has been a driver in patient confusion about access to care, quality, and efficacy.

For example, as reported in the New York Times, robotic surgery for hysterectomy has been heavily advertised. Surgeons promise that using the daVinci robotic device will bring better results and an easier recovery, and many hospitals claim that patients will experience less pain and fewer complications, so patients have a shorter recovery period.[52] A recent study was conducted to evaluate outcomes in more than a quarter of a million American women, who had either laparoscopic or robotically assisted hysterectomy at 441 hospitals between 2007 and 2010.[53] The researchers found no overall difference in complication rates between the two groups, and no difference in the rates of blood transfusion, even though one of the claims regarding robotic surgery is that it causes less blood loss. The cost of the robotic surgery is greater.[54]

A number of studies reveal the dilemma of the uninformed consumer in making healthcare decisions that may result in higher cost, but not higher quality care. The Dartmouth Atlas has conducted research studies that substantiates there can be high quality with less cost.[55] The ABIM Foundation has launched a Choosing Wisely initiative to help physicians and patients engage in conversations to reduce overuse of tests and procedures, and support physician efforts to help patients make smart and effective care choices.[56] There is an established correlation between overtreatment and potential patient harm. Seventeen leading medical specialties have identified specific tests, procedures or medication therapies that are commonly ordered but which are not always necessary and could cause undue harm. [57]

Consumer Reports has made an effort to provide online consumer friendly access to hospital cost and quality data, including data from Connecticut.[58] While this is a starting point, a great deal of data that would be helpful to consumers is not reported; such as individual physician practices, ambulatory care centers, trends and patterns.

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(b) Ability to pinpoint outliers of overtreatment or inappropriate treatment such as overuse of CT scans or Caesarean sections.

Without access to comparable data, healthcare providers do not know if the care they provide is similar, less than, or better than other providers in the state, region, or nationally. For example, one recent study by the Centers for Medicare and Medicaid Services (CMS) found that patients at Connecticut's John Dempsey Hospital were subjected to combination CT scans, which entails an excess radiation risk, nearly ten times the national average. The hospital was surprised to learn that their standard was not the norm. [59]

Another example is the overuse of antipsychotic drugs. Nursing home administrators in Connecticut did not realize that the state ranked sixth highest in the country in the use of these drugs in our nursing homes. [60] Having learned of systemic overuse, our state's Patient Safety Organization established a collaborative effort to reduce inappropriate medications.[61]

Physicians, like facilities, often do not know that they are outliers in the efficacy, safety, and quality of care provided. The Childbirth Connection has researched early inductions, C-section rate, and normal deliveries. Because it is so prevalent in our state, Connecticut hospitals were not aware they had a high rate of C-sections and early delivery and fell outside the norm of other states.[62] These examples of practice pattern outliers that impact patient safety were identified from CMS data, which although limited to Medicare and Medicaid health encounters, provides a powerful example of why data is important to both patients and providers.

(c) Access to physician and facility information with optimum outcomes in specific areas such as joint replacement and back surgeries,

Infection rates of hospitals, nursing homes and ambulatory care centers are indicators of quality and safety important to patients. As the population ages, the CDC is particularly concerned about infection rates in joint replacements. CMS has concerns about physicians who are implanting devices but whose outcomes are not meeting evidence based care or standards.[63]

Access to individual physician outcomes for specific procedures as well as identifying post-surgical infection rates are examples of how the APCD can impact patient safety work.

(d) Observation of care patterns and regional variations in care patterns to identify and learn from best practices.

Dr. Atul Gawande reported on variations within the same hospital for the same procedure and the industry's failure to establish which treatment was most effective.[64] Even when treatment

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efficacy was established, for knee replacement, for instance, other physicians within the same hospital did not make changes in their delivery of care.[65]

(e) Economic analysis of the cost of care and the cost of preventable medical error. Access to and analysis of APCD data can bring greater understanding of the efficiency and effectiveness of health care delivery. The Dartmouth Atlas Project has documented glaring variations in how medical resources are distributed and used in the United States.[66] The project uses CMS data to provide information and analysis about national, regional, and local markets, as well as hospitals and their affiliated physicians. According to the Dartmouth Atlas Project, "This research has helped policymakers, the media, health care analysts and others improve their understanding of our health care system."[67] The APCD can provide similarly comprehensive data for our state's researchers in order to improve the safety of our patient population.

The Pennsylvania Cost Containment Council is an independent state agency responsible for addressing the problem of escalating health costs, ensuring the quality of health care, and increasing access for all citizens regardless of ability to pay. [68] As an example, patients can research physician and facility outcomes for hip and knee replacement. Our APCD could serve the same function in our state.

(f) Conflicts of interests that might be driving prescribing or testing patterns.
The medical device and pharmaceutical industries distribute millions of dollars to physicians. In 2011, over $10 million dollars was distributed to Connecticut physicians from drug companies alone.[69] With access to data, researchers can correlate the introduction of a new drug with pharmaceutical sales practices, and discover if there is a pattern of inappropriate prescribing by an individual physician. As important, the data could expose a link between tests and whether or not the referring doctor has a financial stake in the testing lab.

IV. Recommendations for using the APCD for Patient Safety work

Based on our findings, we recommend:

- The APCD allow initial access by all statutorily mandated users and develop a plan for this access concurrent with CTHIX access. These users include patient safety and quality stakeholders: consumers, employers, advisors, advocates, researchers, and the media.

- The APCD involve consumers and patient safety stakeholders in the design and development of reports and tools relevant and useful for making healthcare decisions.

- Establishment of a Patient Safety Collaborative with non-financially conflicted members to publish an annual Patient Safety Data Scan based on APCD data so that evidence can be translated into health systems change, improved outcomes, and reduced patient harm.

- Increased public education on available patient safety information and new public education campaign to coincide with the launch of APCD consumer tools, to counteract industry marketing.

- The APCD take necessary steps to operate as an independent authority and trusted data source, without industry bias.

Using the APCD to Further Health Equity Work

I. Introduction

It is widely documented and nationally accepted that (1) racial and ethnic disparities exist in our health care system[70] and (2) patients with limited English proficiency are at increased risk for medical and medication errors as well as poorer health outcomes.[71] If designed with health equity in mind, the APCD can provide the means to measure performance toward goals at the provider, insurance plan, program, and state levels.

Collection of demographic data such as race, ethnicity, and language preference provides the opportunity for researchers to stratify analyses across health systems, to identify health disparities, and provide evidence for public health and institutional interventions. According to the Institute of Medicine's Subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality Improvement, "the resultant analyses can be used, for example, to plan specific features of interventions (e.g., the use of culturally relevant content in outreach communications about preventive services) and to compare the quality of care being provided by various entities serving similar populations. The primary reason for standardizing categories for the variables of race and ethnicity is to enable consistent comparison or aggregation of the data across multiple entities (e.g., state-level analyses of providers under Medicaid or a health plan's analysis of disparities in multiple states where it is operating). At the same time, standardized categories must enable persons to self-identify with the categories and increase the utility of the data to the entity collecting them."[72]

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Health equity/disparities centric data can be collected at the point of enrollment into health insurance programs, as well as at the point of care. However, the collection of this data is not currently standardized, and it appears that efforts to do so are increasingly found at the state level in order to provide for locally relevant granularity.

II. Research Approach

We conducted interviews with health equity/disparities stakeholders in two phases; first with states with established APCDs and then with health equity/disparities stakeholders in the state of CT.

In Phase I, health equity/disparities stakeholders in nine states with established APCDs were contacted in an effort to understand (1) their level of involvement in their state's design of the collection, reporting, and access to health data, (2) specific data requirements useful to their work, (3) the extent to which they are using the APCD to inform their work, and (4) the methods/modes of access they have to APCD data. Stakeholders represented non-profit or public sector agencies engaged in minority health, health disparities, and health equity.

In Phase II, health equity/disparities stakeholders in the state of Connecticut were contacted in an effort to understand (1) their level of awareness of the APCD, (2) their level of involvement in the APCD design for the collection, reporting, and access to health data, (3) specific data requirements useful to inform their work, and (4) the methods/modes of access to APCD data they envisioned having.

III. Findings

Phase I – Stakeholders in states with established APCDs
We found that (1) the level of stakeholder involvement in the design of states' APCDs ranged from not at all involved to highly engaged, with varying degrees of data and analytic sophistication, (2) data capture most useful to health disparities work is race, ethnicity, and language preference, (3) a moderate level of frustration with data accuracy and reliability, especially in relation to data coding errors at the source, (4) the ability to access the data in a meaningful way is dependent upon the resource capacity of the stakeholder organization (i.e. people smart about using technology to mine, analyze, and understand data) as well as approval and authority to do so, and (5) additional surveillance type databases and other data sources continue to be used with APCDs.

Before elaborating on each finding, it is important to note that collecting data to inform health equity work isn't a new discipline. As one stakeholder put it, disparities exist in every health discipline. We're not asking anyone to create something entirely different; we just want to look at existing information, differently.[73] For instance, generally accepted and currently collected quality metrics can be stratified for race, ethnicity, and language preference to identify disparities within quality measures. Hospital readmissions are currently tracked and reported; stratified for race, ethnicity, and language preference researchers can identify disparities within readmissions. With access to just three data elements, health disparities researchers can use a new lens to view data for every health encounter; data that has been regularly collected, but previously not accessible.

(1) The level of stakeholder involvement in the design of states' APCDs ranged from not at all involved to highly engaged, with varying degrees of data and analytic sophistication.

Of the nine states reviewed, the most sophisticated involvement in APCD design and use for health equity/disparities work was found in Maryland and Massachusetts.

Maryland has a Health Disparities Collaborative, with a workgroup focused specifically on Research and Evaluation Data. This work group has a membership of some fifty stakeholders from: Schools of Medicine, Public Health, Social Work, and Pharmacy, Medical Society, University Medical Systems, University, Government (Office of Minority Health and Health Disparities), Legislature, Non-Profit Advocacy Groups, Hospital Centers for Health Disparities, National Cancer Institute, Tumor Registry Board, and Policy Institutes.[74] The data workgroup has developed recommendations for (1) the state's health care commission for a standard set of measures for healthplans regarding racial and ethnic variations in quality and outcomes, and (2) for the Health Services Cost Review Commission for usage of racial and ethnic data in evaluating hospital performance and outcomes.[75]

When Massachusetts began designing its APCD, the Department of Public Health (DPH) requested more than one hundred data elements be added to payer submission specifications.[76] In addition to race, ethnicity, and language preference, MA DPH collects patient demographics that are useful to more comprehensive study of health disparities such as sexual orientation, veteran status, immigration status, refugee status, migrant worker status, disability status, and tribal membership. Additionally, they collect provider demographics such as provider type, race, ethnicity, primary language, and other language.[77] Researchers at MA's DPH have been awarded NIH funding to use the APCD to investigate health trauma and disparities.[78]

We found a variety of healthcare cost and quality agencies and councils operating in other states that are unparalleled in our own state; e.g. The Center for Health Information and Analysis (MA), Health Services Cost Review Commission (MD), and Health Disparities Collaborative (MD).

(2) Data capture most useful to health disparities work is race, ethnicity, and language preference.

Stakeholders expressed concern with the consistency of data and the importance of establishing standards across payers and providers for capturing data for comparative purposes. Maryland has adopted the Federal OMB Directive 15[79] as a starting point for race, ethnic, and language data collection; with plans to expand to capture subcategory granularity of ethnicities to more accurately study public health issues and disparities (e.g. Asian versus Cambodian). Massachusetts also standardized data collection of race, ethnicity, and language preference and mandated its collection by all healthcare organizations in 2006.[80]

(3) A moderate level of frustration with data accuracy and reliability, especially in relation to data coding errors at the source.

Stakeholders in states with established APCDs consistently expressed the old adage: garbage-in, garbage-out. Several issues were raised regarding coding for race, ethnicity, and language preference: (1) collecting these data elements at the point of encounter rather than at the point of enrollment/eligibility led to observer-reported rather than self-reported data; (2) self-reported data is deemed more reliable for race, ethnicity, and language preference but is difficult to collect at point of encounter, when treating the patient outweighs having the patient fill out more demographic paperwork; (3) due to the observer-reported data coding and overall lack of training of healthcare providers and administrators to code for race, ethnicity, and language preference, one state reported that the number of "unknown" encounters was greater than the known; (4) some states reported the need for usage of a consistent data set for race and ethnicity across all stakeholders such as the federal OMB standards; (5) once epidemiologists in one state discovered that race and ethnicity data elements were unreliable due to coding errors, health/equity stakeholders could not risk using the data to inform their work; (6) one state established an APCD data work group to create a companion to the data dictionary, that scores each data element in the APCD for reliability, accuracy, and completeness in an effort to assist researchers and stakeholders in their analysis; (7) one state is working on developing a public report card on data quality and completeness of payer submissions; and (8) one state is working on a researcher's guide to the APCD, to define how the data elements can be used in combination with others to answer specific health research questions.

(4) The ability to access the data in a meaningful way is dependent upon the resource capacity of the stakeholder organization (i.e. people smart about using technology to mine, analyze, and understand data) as well as approval and authority to do so.

Stakeholders consistently mentioned the need for epidemiologists to study APCD data to inform health equity/disparities work through causal analysis rather than fishing expeditions. Economists to provide cost of disparity (severity, frequency) analyses were also mentioned. Although stakeholders want access to data, many budgets can't support skilled research staff with the ability to mine, analyze, and adjust data for socioeconomic factors, develop meaningful metrics and dashboards, and spot random fluctuations. One stakeholder reflected the importance of having people that were "smart about data" to determine if the APCD data was stable enough to draw meaningful conclusions for program and policy work. Without skilled research staff, stakeholders fell mainly into two categories: those that didn't trust the data at all and those that used it without question.

Many stakeholders reported they were required to sign data use agreements in order to access APCD data. Flat file DVDs, SQL, and SAS were the most oft-mentioned access and analysis software.

Maryland currently publicly reports health outcome, healthcare process, and patient experience measures on public sector and state hospital association websites, and plans to analyze and identify disparities in each category of reporting as well as benchmark measures on a state and national level.[81]

Massachusetts conducts regularly scheduled technical and analytic webinars with on-line registration and feedback loops open to APCD researchers and payers. Researchers prefer the ability to perform individualized queries of the APCD data to maximize its utility, with data refreshes available on a monthly basis.

(5) Additional surveillance type databases and other data sources continue to be used with APCDs.

The APCD does not replace the use of other databases, but rather provides a more comprehensive and integrated view of all health encounters, instead of only Medicaid or only inpatient encounters. In Massachusetts, other databases are being integrated with the APCD for comprehensive analysis.

Phase II – Stakeholders in CT

In speaking with health equity/disparities stakeholders in the state of Connecticut, we found that (1) the level of awareness of the APCD amongst health equity/disparities stakeholders varied widely from, "what is an all payer claim database?" to "I've attended the meetings", (2) none of the health equity/disparities stakeholders we spoke with had been involved in APCD design decisions for the collection, reporting, and access of data needed to inform their work, (3) the health equity/disparities stakeholders we spoke with had not convened to collaborate on recommendations for data requirements for the APCD, and (4) none of the health equity/disparities stakeholders we spoke with knew what methods/modes of access would be available to them once the APCD was established.

Before elaborating on each finding, it is important to note that the APCD is in early stages of development in the state of Connecticut. This provides health equity/disparities stakeholders the opportunity to engage in the design to make the database ultimately useful to identify and analyze disparities across regions, providers, and populations, as well as to measure and evaluate the impact of programs designed to eliminate disparities.

(1) The level of awareness of the APCD amongst health equity/disparities stakeholders varied widely from, "what is an all payer claim database?" to "someone in our organization attends the meetings".

The health equity/disparities stakeholders we spoke to were not at all, vaguely, generally, or very aware that an initiative was underway to build a database that could provide evidence basis for their work. However, even among the very aware there was an absence of a meaningful path to participation in the APCD design and development.

(2) None of the health equity/disparities stakeholders we spoke with had been involved in APCD design decisions for the collection, reporting, and access of data needed to inform their work.

Even when health equity/disparities stakeholders were aware of the APCD or regularly attended APCD meetings, we found no stakeholders that were actively engaged participants in decisions and recommendations in the early design stage of the database and supporting technology. One stakeholder that regularly attended APCD Advisory Group meetings commented that there were no discussions on specific health disparities data elements or requirements, and there were no health equity/ disparities data or reporting work groups or committees.

Yet, there are innovations taking place concurrently that may benefit from closer linkages with APCD efforts. For example, the Connecticut Association of Directors of Health has developed a health equity index, providing municipal health directors on-line access to community-specific

measures of social determinants of health and health outcomes. [82] Imagine the information that could be disseminated by integrating APCD data with this tool?

(3) The health equity/disparities stakeholders we spoke with had not convened to collaborate on recommendations for data requirements for the APCD. The APCD received letters from the Connecticut Health Foundation and a number of other stakeholders regarding their interest in having the APCD support research on health disparities, however the letters "didn't get into detail".[83] There was a lack of collective awareness across and within stakeholder organizations of what others were doing or thinking about the database.

The Connecticut Commission on Health Equity's legislative mandate provides the authority to collect and analyze racial and ethnic health disparities data across all state agencies.[84] However, the Commission was not included in APCD use case interviews, was not a member of the Advisory Group, and did not participate in APCD meetings.[85] The Commission established a data work group in 2010, however this data work group has not been involved in the APCD project.[86]

The DPH's Office of Health Equity Research, Evaluation, and Policy collaborates with the DPH's Office of Healthcare Access to keep tabs on the APCD development through Advisory Group meetings, however to-date has not participated in the development or submission of specific requests for data elements, reports, or access to health equity/disparities centric data.[87] Data elements that would be useful to state stakeholders mirrored that of other states: race, ethnicity, language preference, disability status, age, gender, and income.

(4) None of the health equity/disparities stakeholders we spoke with knew what methods/modes of access would be available to them once the APCD was established.
One stakeholder that regularly attended APCD Advisory Work Group meetings reported there were no discussions on issues of resource or technology capacity for stakeholders to mine, analyze, report, and otherwise meaningfully use APCD data.

(5) A number of other databases are currently used to analyze health disparities.
One stakeholder commented that the state already has more data than people to analyze it, and did not know who would take on the role of mining the APCD for health equity/disparities analyses. This echoes our findings in states that didn't fully utilize their APCDs due to a lack of resources. Others commented that there are questions regarding the reliability and validity of hospital discharge data currently received, and that data is limited to inpatient admissions.

IV. Recommendations for using the APCD to further Health Equity work

Access to data is critical for understanding the nature and extent of health disparities across populations in our state. Local benchmarking will raise awareness and highlight areas for examination to drive quality improvement for all patients.

Race and Ethnicity are APCD Council core data elements. Race, Ethnicity, and Language Preference are (1) identified enrollment/eligibility data elements for CT's health insurance exchange,[88] and (2) required of hospitals participating in CMS' Electronic Health Record Incentive Program.[89]

Based on our findings, we recommend:

- An academic or independent research organization convene a Health Disparities Data Collaborative across silos of health equity stakeholders to integrate and promote data priorities and recommendations, and specifically to inform the design and use of the APCD including: data definition, data collection, data mining, data reporting, and data access.

- The Collaborative address three core areas for disparities data analysis and reporting: quality, outcomes, and costs.

- The Collaborative develop shared services initiatives for stakeholders lacking resource and technology capacity to access, mine, and analyze data for disparities program work. These initiatives could include web-based research workshops and researcher guides to the APCD.

- The Collaborative work to adopt consistent definitions, standards, and data sets for race, ethnicity, language preference and other data useful to collective work.

- The collaborative support policy change and enforcement mandating all payers in the state collect demographic data at point of enrollment that minimally includes race, ethnicity, and language preference.

- The Collaborative support policy change to use race and ethnicity data in evaluating hospital performance.

APCD Access & Reporting

I. Introduction

The US spends more per capita on health care than any other country, 2.5 times the average for industrialized countries. [90] Within the highest cost country, health costs in Connecticut are among the highest; only Massachusetts, Alaska, and the District of Columbia spend more per resident on health care. [91] One in three Americans lives in a family experiencing the financial burden of medical care. [92] 300,000 Connecticut residents have no insurance coverage to pay growing healthcare costs [93], and a rising number of consumers are in high deductible plans. Both uninsured and underinsured consumers are at full financial risk for a significant portion of their medical bills. Uninsured and self-pay patients are charged the highest prices for care and comparison-shopping is nearly impossible. [94]

A recent analysis rated Connecticut among twenty- six states that received an F grade in price transparency laws for consumers.[95] Both states that received an A, Massachusetts and New Hampshire, have APCDs with consumer portals. The APCD could offer tools to help consumers evaluate costs and shop for price, driving down costs for the entire market. Three state APCDs, Massachusetts, New Hampshire and Maine, include a public portal providing consumers the ability to find realistic prices for medical services in their area. [96]

Responding to out of control health costs, self-insured employers are reforming the way they pay for care; paying for quality rather than volume, and bundling care for an episode or by patient to align incentives to control costs and reduce fragmentation and overtreatment.[97] The APCD could provide self-insured employers the tools to design, monitor and learn from payment reform to use their collective power to control costs both for their employee populations and across the entire system.

II. Research Approach

We surveyed stakeholders in states with APCDs and in Connecticut regarding APCD access, reporting, and anticipated and current data uses.

III. Findings

We found (1) consumers have little to no information about health care costs or quality,[98] (2) there is no published timeline for "Tier 3" stakeholder access to CT's APCD data, (3) a number of stakeholder uses for APCD data, and (4) clear data access security protocols.

(1) Consumers have little to no information about health care costs or quality.
A growing number of consumers are directly financially responsible for the costs of their own care. Payment reform proposals rely on consumers shopping for care creating market pressure to increase value.[99] New Hampshire, Massachusetts and Maine have used their APCDs to create web-based health care cost and quality look-ups for consumers.

(2) There is no published timeline for "Tier 3" stakeholder access to APCD data.
Although many stakeholders anticipate accessing APCD data, the APCD Advisory Group outlined a tiered process that appears to exclude all but the CTHIX from accessing APCD data to conduct research, develop analyses, and create reports in 2014-2015. [100]

- Tier 1 reports will show data at the population level, statewide or for large regions. Tier 1 reports will be publicly available, are expected in mid-2014 and will be refreshed quarterly.[101]

- Tier 2 reports include additional detail on Tier 1 reports with analytic tools such as groupers and risk adjustment. Tier 2 reports could include comparisons of cost for common procedures, tools to help consumers choose high value providers, and analyses of the impact of public policy changes. Tier 2 reports are expected to be available in early 2015 and refreshed twice each year.[102]

- Tier 3 includes access to research data sets, including custom datasets. Tier 3 data will be available through an application process guided by a Data Release Advisory Committee convened by the APCD administrator. Proposed regulations direct that the Committee shall include representatives of insurers, facilities, physicians, consumers, employers, researchers, Medicaid, and pharmacy. [103]

Connecticut state statute mandates the APCD utilize data to provide health care consumers with information regarding the cost and quality of healthcare services. We interpret this to mean *all* health care consumers, not the limited subset of CTHIX enrolled consumers. Statute also

mandates the data be made available to state agencies, insurers, employers, health care providers, consumers of health care services, researchers, and the CTHIX. [104]

This is an opportunity for stakeholder engagement with the APCD Advisory Group.

(3) A number of stakeholder uses for APCD data.

An APCD can be a powerful tool. Examples of state APCD uses to reform health systems include evaluation of patient-centered medical homes (NH), rate review comparing trends and setting benchmarks (discussions in NY, VT, and NH), and guiding decisions about new payment models such as Accountable Care Organizations, global budgeting, baseline costs and quality adjusted payments (NH). Consumer uses of APCD data included health care cost look-up based on actual paid claims (NH, ME, and MA).

The anticipated uses of APCDs include (1) tracking performance and quality across providers and payers, (2) conducting comparative effectiveness research to identify best practices, (3) risk adjusting rates between plans, (4) monitoring plans for evidence of adverse selection and marketing abuses, (5) studying the relationship between benefit structure and care delivery, and (6) identifying which preventive services are utilized and effective. [105]

Stakeholders we spoke with were interested in using the APCD to (1) identify and evaluate care coordination patterns and structures, (2) identify the boundaries of problems identified, drill down to identify sources and solutions, (3) identify outliers/hot spots – positive and negative – allowing for investigation to build a learning system and identify best practices, (4) identify and reduce overtreatment and inappropriate care, (4) learn how far people travel for care, especially by payer, and use incentives to develop capacity to fill gaps, (5) evaluate effectiveness, including cost effectiveness, of policy initiatives and introduction of new technologies, (6) compare utilization patterns between populations and payers, (7) identify primary and specialty care provider shortage areas, and learn how patients are getting care in those areas, describe the impact, and target resources, (8) find gaps in local disease prevention programs to better target resources, (9) find prevention programs that are performing well to share best practices with all and duplicate in communities with need, and (10) to perform more sophisticated risk adjustment between plans.

The APCD Advisory Group identified a number ways APCD data could be used to improve health delivery systems, (1) reducing the cost of ER admissions, (2) comparisons of care between Medicaid and commercial populations, (3) evaluating effectiveness of prevention strategies, (4) identifying emerging trends and epidemics, (5) developing programs to address chronic

conditions, (6) modifying benefit design to improve value, (7) improving Medicaid delivery models, (8) optimizing useful information for primary care providers, (9) improving cost and quality profiles between populations, and (10) tracking costs by episode of care.[106]

In terms of health equity/disparities, all of the above-mentioned analyses can be stratified for race, ethnicity, and language preference for CTHIX enrolled members, if the CTHIX enrollment/eligibility system is designed to collect these data elements as included in the Single Streamlined Application (SSA) created by HHS.[107] However, the CTHIX population is anticipated to be just eight percent of the health consumer population in the state. Until/unless these data elements are required for all commercially enrolled populations, health equity/disparities stakeholders will not have optimal access to data required to inform evidence based interventions.

We could not find a companion list of consumer uses of APCD data identified by the APCD Advisory Group, and believe this is an opportunity for heightened stakeholder engagement.

(4) Clear patient and payer data security.
Established APCDs have protocols for controlling data access, and many have data use agreements. MA publicly posts requests for data on the APCD website, identifying the data requestor, intended use, and an opportunity for public comment.[108] To protect privacy and security, Minnesota does not allow the release of detailed data beyond the authorizing state agency. States can impose appropriate, significant penalties for misuse or disclosures. [109]

IV. Recommendations for APCD Access & Reporting

Based on our findings, we recommend:

- Constructing an APCD consumer portal to allow comparisons of health services locally by cost and quality, grouped in ways that make sense to consumers, with plain language explanations.

- Creating a process for public and stakeholder input into Tier 1 and Tier 2 reports and priorities for data use to ensure the APCD meets the needs across the state's health system.

- Staffing of APCD resources with analytic capacity to ensure that the power of the database to improve Connecticut's health system is utilized to its fullest extent.

- Establishing a mechanism for public review and comment for data use applications.

- Tracking data use agreements to ensure compliance with data usage terms, establishing penalties for inappropriate use, and public reporting of commercial uses of data.

- Educating public users, including workshops on how to access data through the APCD with feedback loops to improve ease of use and usefulness.

- Policy change to mandate APCD use for Connecticut Insurance Department premium   rate review.

About this Project

This research was a collaborative effort undertaken by the Connecticut Center for Patient Safety and the Connecticut Health Policy Project, with funding provided by the Connecticut Health Foundation.

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For eight years, the CTCPS, www.ctcps.org, has worked to promote patient safety, improve the quality of healthcare, and protect the rights of patients in Connecticut. CTCPS participates in health reform and innovation forums at the state, regional, and national level, including: NQF, NCQA, AHRQ, IHI, PCORI, Consumers Union, and CDC.

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For thirteen years, the CTHPP, www.cthealthpolicy.org, a non-partisan research and educational organization, has been dedicated to improving access to affordable, quality health care for all Connecticut residents. CTHPP participates in health reform and innovation forums at the regional, state and local level, including: Council of State Governments/Eastern Region Health Policy Committee, CT Medicaid Assistance Program Oversight Council, New England Comparative Effectiveness Public Advisory Council, and New Haven City Benefits Advisory Committee.

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Comparative Analysis State APCDs

State APCD	Race Ethnicity	Data Included	Data Sources	Funding	Structure Who Runs
CO APCD www.cohealthdata.org	UNK	Medical, Rx	Medicare (in process), Medicaid, commercial	Foundations	Nonprofit, came from Executive Order Council
KS Data Analytic Interface http://www.kdheks.gov /hcf/data_consortium/d efault.htm	UNK	Medical Dental Rx	Medicaid, commercial, state employee plan	State	State agency
MA APCD http://www.mass.gov/d hcfp/apcd	Yes	Medical Dental Rx	Medicare, Medicaid (June), private payers – most MA residents	User fees for accessing data, not likely to fund all	State DHHS, Div of Health Care Finance & Policy
MD MD Health Care Commission Medical Care Database http://mhcc.dhmh.maryl and.gov/SitePages/Hom e.aspx	Yes	Medical Dental Rx	Medicare, Medicaid, commercial	State	MD health care commission – state agency
ME ME Health Care Claims Database http://mhdo.maine.gov/ imhdo/	Yes	Medical Dental Rx	Medicare, Medicaid, commercial, partial uninsured***	State	Separate state agency, Governing Board of payers, providers and consumers
MN Health Care Claims Reporting System http://www.health.state. mn.us/healthreform/enc ounterdata/index.html	No	Medical Rx	Medicare, Medicaid, commercial	State	State agency
NH NH Comprehensive Health Care Information System CHIS https://nhchis.com	Yes	Medical Dental Rx	Medicaid, commercial	State	Insurance and Health Depts
NY http://www.health.ny.go v Got $95 million from HIX grant, built on hospital discharge DB with Medicaid DB new procurement	TBD	Medical	Medicaid and commercial by end of yr, Medicare next year w new application	Federal exchange grant	State public health agency, in collaboration w/ HIX
OR APCD http://www.oregon.gov/ OHA/OHPR/RSCH/Pages	Yes	Medical Rx	Medicaid, Medicare, commercial	State	State agency

/APAC.aspx					
TN APCD http://www.tn.gov/finance/healthplanning/	No	Medical Rx	Commercial	State	State agency
Utah APCD http://health.utah.gov/hda/apd/index.php	No	Medical Rx	Commercial, Medicaid	State	State agency
VT The Vermont Healthcare Claims Uniform Reporting and Evaluation System (VHCURES)	TBD	Medical Rx	Commercial	State	State agency

Endnotes

[1] State of Connecticut General Assembly. (2012). *An Act Implementing the Governor's Budget Recommendations Concerning An All-Payer Claims Database Program.* Available at http://www.cga.ct.gov/2012/ACT/PA/2012PA-00166-R00HB-05038-PA.htm

[2] Ibid.

[3] Agency for Healthcare Research & Quality, *Highlights from the 2011 National Healthcare Quality and Disparities Reports.* Available at http://www.ahrq.gov/qual/nhdr11/key.htm

[4] Consumers Reports "How Safe is Your Hospital?" Available at http://media2.wcpo.com/pdfs/CRHospitalsAug2012.pdf

[5] Agency for Healthcare Research & Quality, *Highlights from the 2011 National Healthcare Quality and Disparities Reports.* Available at http://www.ahrq.gov/qual/nhdr11/key.htm

[6] Ibid.

[7] Ibid.

[8] Ibid.

[9] APCD Council, Available at http://www.apcdcouncil.org/

[10] Patient Protection and Affordable Care Act, Available at http://www.gpo.gov/fdsys/pkg/PLAW-111publ148/content-detail.html

[11] Love, D. et.al. *All Payer Claims Databases: State Initiatives to Improve Health Care Transparency*, Commonwealth Fund, September 2010

[12] Conversation with Ellen Andrews and APCD Council, 01/28/13

[13] Ibid.

[14] Ibid.

[15] The Commonwealth Fund, *Whynothebest?,* Available at http://www.whynotthebest.org/about

[16] Ibid.

[17] Love, D. et.al. *All Payer Claims Databases: State Initiatives to Improve Health Care Transparency*, Commonwealth Fund, September 2010

[18] Conversation with Ellen Andrews and APCD Council, 01/28/13

[19] FairHealth, Available at http://www.fairhealthconsumer.org.

[20] Conversation with Ellen Andrews and Rachael Block, NY APCD, 02/06/13

[21] CT APCD Advisory Group, Meeting Minutes, 07/12/12

[22] CT APCD Advisory Group, Available at http://www.healthreform.ct.gov/ohri/cwp/view.asp?a=2742&q=333608

[23] Access Health CT Strategy Committee, *CT All Payer Claims Database: Overview & Opportunities for Innovation*, 2/21/13.

[24] CT All Payer Claims Database: Overview & Opportunities for Innovation, Access Health CT Strategy Committee, 2/21/13

[25] Joint Commission, *Improving America's Hospitals: The Joint Commission's Annual Report 2012*, Available at http://www.jointcommission.org/annualreport.aspx

[26] Special Congressional Field Hearing, Committee on Aging, July 2012, Jean Rexford Testimony, Available at http://www.aging.senate.gov/events/hr248jr.pdf

[27] Ibid.

[28] Ibid.

[29] Ibid.

[30] Agency for Healthcare Research and Quality, *AHRQ Priorities for National Action*: Available at http://www.ahrq.gov/professionals/quality-patient-safety/patient-safety-resources/resources/iompriorities.pdf

[31] Conversation with Jean Rexford and Arthur Levin, MPH and Director of Center for Medical Consumers, http://medicalconsumers.org/about/

[32] Chedekel, L., *Connecticut Hospitals Don't Make 'Top Performer's List*, C-HIT, 2012, Available at http://c-hit.org/?s=no+hospitals+designated+as+top+performers

[33] Joint Commission Report on Top Performing Hospitals 2012. Available at

http://www.healthcareitnews.com/news/joint-commission-spotlights-620-top-performing-hospitals

[34] Chedekel, L., *State Hospitals Face Second Highest rate of Federal Penalties Nationwide*, C-HIT, January 2013, Available at http://c-hit.org/?s=state+hospitals+face+penalties

[35] Rau, J. *Kaiser Health News*, Available at http://www.kaiserhealthnews.org/Stories/2012/December/21/medicare-hospitals-value-based-purchasing.aspx

[36] Ibid.

[37] State of Connecticut Department of Public Health, *Connecticut Adverse Event Report,* 2012. Available at http://www.ct.gov/dph/lib/dph/hisr/hcqsar/healthcare/pdf/adverseeventreport2012.pdf

[38] Consumers Reports, *Deadly Infection Still Too Common in U.S Hospitals*, February 2013. Available at http://news.consumerreports.org/health/2013/02/deadly-hospital-infections-are-down-but-still-too-high-in-most-hospitals.html

[39] National Health Safety Network, Available at https://www.premierinc.com/quality-safety/tools-services/safety/topics/HAI/#HHS_Action

[40] National Action Plan, Available at http://www.hhs.gov/ash/initiatives/hai/actionplan/index.html

[41] Peng, L., MD, *Outpatient Surgery*, emedicinehealth. Available at http://www.emedicinehealth.com/outpatient_surgery/article_em.htm

[42] Chedekel, L., Yale study: Medication errors, confusion common for hospital patients, *New Haven Register,* December 3, 2012. Available at: http://nhregister.com/articles/2012/12/03/news/doc50bd213d5f662015750301.txt?viewmode=default

[43] Conversation with Jean Rexford and Charles Bell, VP Policy Consumers Union, January 2013

[44] Conversation with Jean Rexford and Paul Grady, Partner, Mercer January 2013

[45] Think about it Colorado Campaign, Available at http://www.thinkaboutitcolorado.org/

[46] Pennsylvania Cost Containment Council, Available at http://www.phc4.org/

[47] Legislative Report to the General Assembly: *Quality in Healthcare Improvement: 2011.* Available at http://www.ct.gov/dph/lib/dph/hisr/hcqsar/healthcare/pdf/adverseeventreport2011.pdf

[48] CT General statutes, Section 19a-127l. Available at http://www.cga.ct.gov/

[49] Levinson, D. Inspector General: *Adverse Events in Hospitals: National Incidence among Medicare Beneficiarie*s. Available at https://oig.hhs.gov/oei/reports/oei-06-09-00090.pdf

[50] The Leapfrog Group, Available at http://www.hospitalsafetyscore.org/

[51] Hospital Safety Score, *Connecticut Hospitals*, Available at http://www.hospitalsafetyscore.org/searchresult?zip_code=&hospital=&city=&state_prov=CT&agree=agree

[52] Rabin, R.C., Questions About Robotic Hysterectomy, *The New York Times*, 02/25/13, Available at: http://well.blogs.nytimes.com/2013/02/25/questions-about-a-robotic-surgery/

[53] Ibid.

[54] Martenson, C., *Healthcare Costs Consume Nearly 18% of US Economy*, The Independent Report, January 2011. Available at http://independentreport.blogspot.com/2011/01/health-care-costs-consume-nearly-18-of.html

[55] Rabin, R., *Questions about Robotic Hysterectomy*, NY Times Well Blogs, February 25, 2013. Available at http://well.blogs.nytimes.com/2013/02/25/questions-about-a-robotic-surgery/

[56] Dartmouth Atlas. Available at http://www.dartmouthatlas.org/

[57] ABIM Foundation, *Choosing Wisely*, Available at http://www.abimfoundation.org/Initiatives/Choosing-Wisely.aspx

[58] CT Hospital specific data are available at http://www.consumerreports.org/health/doctors-hospitals/hospital-ratings/ratings/search-results.htm?state=CT

[59] Chedekel, L. *UConn's Dempsey Hospital Off The Charts In Controversial "Double CT Scan"*

Use. Connecticut Health I-Team, 01/28/2011. Available at http://chit.org/2011/01/28/uconns_dempsey_hospital_off_the_charts/

[60] Chedekel, L., *High Use of Antipsychotics in CT Nursing Homes*, Connecticut Health I-Team, 01/30/2013. Available at http://c-hit.org/2013/01/30/high-use-ofantipsychotics-in-nursing-homes-stirs-concerns-reforms/

[61] Qualidigm, Antipsychotic drug collaborative, Available at http://www.qualidigm.org/index.php/currentinitiatives/cms-antipsychotic-initiative/

[62] Childbirth Connection. Report Available at http://www.cesareanrates.com/storage/state_pdfs/Connecticut_Cesarean_Rates_Report.pdf

[63] Wilson, N.A., Schneller, E.S., et. al. Hip And Knee Implants: Current Trends And Policy Considerations, *Health Affairs*. Available at http://content.healthaffairs.org/content/27/6/1587.full

[64] Gawande, A., Big Med, *New Yorker*, August 2012. Available at http://www.newyorker.com/reporting/2012/08/13/120813fa_fact_gawande

[65] Ibid

[66] Dartmouth Atlas, Available at http://www.dartmouthatlas.org/

[67] Ibid

[68] Pennsylvania Health Care Cost Containment Council, Available at http://www.phc4.org/hipknee/

[69] Merrill, J.B., Ornstein, C., et.al., *Docs Get Pharma Perks,* ProPublica, March 11, 2013. Available at http://c-hit.org/2012/07/28/40_of_highprescribing_docs_get_pharma_perks
(CT specific information available at http://projects.propublica.org/docdollars/)

[70] Smedley, B., *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, IOM, 2002

[71] Ibid.

[72] Cheryl Ulmer, Bernadette McFadden, and David R. Nerenz, Editors; Subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality Improvement; Institute Of Medicine IOM, "Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement. 2009Retrieved at: http://www.nap.edu/catalog.php?record_id=12696

[73] Conversation with Brenda Shipley and David Mann, PhD January, 2013

[74] Maryland Health Disparities Data Collaborative, *Report on Secretary's Request for Assistance*, August 10, 2012

[75] Ibid.

[76] Conversation with Brenda Shipley and Sylvia Hobbs, MPH, 01/25/13

[77] Ibid.

[78] Ibid.

[79] Conversation with Brenda Shipley and David Mann, PhD, January 2013

[80] Massachusetts Department of Public Health, *"Implementing New Race, Ethnicity, and Language Data Collection Standards"*, 2006. Available at: http://www.mass.gov/eohhs/docs/dph/health-equity/race-ethnicity-language-dta.pdf

[81] Maryland Health Disparities Data Collaborative, *Report on Secretary's Request for Assistance*, August 10, 2012

[82] Conversation with Brenda Shipley and Sharon Mierzwa, February, 2013; also see http://www.cadh.org/health-equity/health-equity-index.html

[83] Correspondence with Brenda Shipley and Roberta Schmidt, 02/18/13

[84] Connecticut General Statutes, Sec. 38a-1051, Commission on Health Equity.

[85] Correspondence with Raja Staggers-Hakim and Brenda Shipley, 02/26/13

[86] Ibid.

[87] Conversation with Brenda Shipley and Margaret Hynes, February, 2013

[88] CMS, *Single Streamlined Application for the Health Insurance Marketplace: Guidance for Online Application*, Version 1.0, December 14, 2012

[89] CMS, eHR Incentive Program, *Meaningful Use Core Measures, Measure 7 of 15, Demographics*,

41

November 7, 2010. Available at http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/downloads/7_Record_Demographics.pdf

[90] OECD, *Frequently Requested Data*, 2012 report, 2010

[91] CMS, *2009 Health Expenditures by State of Residence*, 2011

[92] CDC, *Financial Burden of Medical Care: Early Release of Estimates From the National Health Interview Survey January–June 2011*, March 2012

[93] CT Health Policy Project Brief, September 2012

[94] Health Care Price Transparency: Meaningful Price Information Is Difficult for Consumers to Obtain Prior to Receiving Care, GAO, September 2011

[95] Report Card on State Price Transparency Laws, Catalyst for Payment Reform & Health Care Incentives Improvement Institute, March 2013, http://www.hci3.org/content/report-card-state-price-transparency-laws

[96] P. Miller, *All Payer Claims Databases: An Overview for Policymakers*, Academy Health, May 2010

[97] Value over Volume, CSG/ERC, 2009, www.valueovervolume.org

[98] GAO, *Health Care Price Transparency: Meaningful Price Information Is Difficult for Consumers to Obtain Prior to Receiving Care*, September 2011

[99] APCD Council, CEPAC, Miller, May 2010, *Buried Treasure: Freeing California Data to Improve Health Care, California Health Foundation,* May 2012, Love, September 2010, *What's the Price of Health Care?*, Robert Wood Johnson Foundation, August 2012

[100] APCD Advisory Group, Meeting Slides, 12/13/12

[101] Ibid.

[102] Ibid.

[103] Ibid.

[104] State of Connecticut General Assembly. (2012). *An Act Implementing the Governor's Budget Recommendations Concerning An All-Payer Claims Database Program.* Available at http://www.cga.ct.gov/2012/ACT/PA/2012PA-00166-R00HB-05038-PA.htm

[105] Conversation with Ellen Andrews and APCD Council, 01/28/13

[106] APCD Budget & Report on Use Case Interviews, APCD Advisory Group, July 12, 2012

[107] CMS, *Single Streamlined Application for the Health Insurance Marketplace: Guidance for Online Application*, Version 1.0, December 14, 2012

[108] D. Love, et. al., *All Payer Claims Databases: State Initiatives to Improve Health Care Transparency*, Issue Brief, Commonwealth Fund, September 2010; D Love and B Rudolph, *Health Data Systems at a Crossroads*, NADHO, December 2012; P. Miller, et.al., *All Payer Claims Databases: An Overview for Policymakers*, Academy Health, May 2010; APCD Council, interviews.

[109] Miller, P., et. al., *All Payer Claims Databases: An Overview for Policymakers*, Academy Health, May 2010