

NACDD Issue Report on All Payer Claims Databases for Hypertension and Diabetes Surveillance



Cardiovascular Health Program

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Introduction

All Payer Claims Databases (APCDs) are state-level data sources that can potentially enhance traditional chronic disease surveillance efforts by providing patient-level inpatient, outpatient, pharmacy, enrollment, and other administrative claims data across participating health plans. In September 2016, the National Association of Chronic Disease Directors (NACDD), in coordination with CDC's Division for Heart Disease and Stroke Prevention (DHDSP), hosted a conference call in which epidemiologists from six states described their experiences with APCD access and use related to the CDC's 1305 State Public Health Actions grant (1305).

Panelists were selected for the conference call based on the existence of an APCD in their state and their availability and willingness to share their experiences with other epidemiologists on the call. Panelists represented Hawaii, Maine, Minnesota, Rhode Island, Vermont, and Washington.

Tara Ramanathan, from CDC's Public Health Law Program, spoke on the call regarding the 2016 U.S. Supreme Court decision, [*Gobeille v. Liberty Mutual*](#), which addressed the requirements of health insurance plans to report their data, and the potential impact of this on the future of APCDs. Her recommendations for state health departments are available in Appendix B.

The purpose of this report is to present a summary of perspectives on the strengths and limitations of APCDs as surveillance resources for cardiovascular disease and diabetes. Content is based on panelist discussion during the call and additional information collected from the panelists between January and April 2017.

What is the promise of using APCDs for surveillance of cardiovascular disease and diabetes?

Chronic disease programs are charged with monitoring risk factors and disease trends to inform the development of prevention and control programs. This information can be used to develop health department programs, inform program evaluations, and educate the community about disease status/prevalence. For cardiovascular disease and diabetes, the mainstays of state-level surveillance are vital statistics administrative databases, especially mortality and inpatient hospitalization and emergency department (ED) discharge databases.

States supplement these with surveys, often featuring self-reported information, and data collected at the local level. While mortality, hospital, and ED data are useful in demonstrating the impact of cardiovascular disease and diabetes, they do not reveal the full story on diagnosis, prevalence, challenges, and costs associated with living with these conditions. Moreover, they provide information on encounters with the healthcare system rather than on patients. As a result, at best, they show snapshots of a population at a point in care rather than illuminate issues with the care of patients over time. The Behavioral Risk Factor Surveillance System also has provided valuable information for cardiovascular disease and diabetes surveillance, but has limitations, including reporting bias. APCDs add a potentially powerful surveillance tool to the mix. Often including medical, dental, and pharmacy claims, APCDs can fill a need for comprehensive, multi-payer data sources that allow health departments and other stakeholders to understand the cost, quality, and utilization of healthcare among their residents. For example, the Minnesota Department of Health's Health Economics Program has used its APCD to analyze areas such as pharmaceutical spending, factors that drive healthcare spending growth, and potentially preventable healthcare events. States see many options to use APCDs to understand the impact of chronic disease, especially cardiovascular disease and diabetes.

The Hawaii Department of Health intends to use its APCD to understand the prevalence, treatment patterns, and costs associated with chronic diseases, such as diabetes and cardiovascular disease as longitudinal patient conditions. Having a single database for inpatient, outpatient, and pharmacy expenditures strengthens the state's capacity to do this. Because APCDs include denied claims, co-payments, and deductibles, APCDs can also be used to illuminate the out-of-pocket burden on insured patients with chronic disease.

APCDs that are set up to examine episodes of care or track the care of individuals over time can be used to describe healthcare events spanning diagnosis through treatment to health outcomes. The Vermont panelist will be tracking healthcare utilization among individuals who experienced cardiac events to assess and compare the follow up care they receive in primary care, specialty care, or emergency department settings. This could indicate how well their underlying conditions are managed and highlight opportunities to improve follow up and reduce costs.

Surveillance data from multiple payers within an APCD can be used to identify areas of healthcare where disease prevention or management could be improved. For example, the Minnesota panelist would like to use claims data to look at enrollment in Diabetes Self-Management Education (DSME)

relative to the proportion of patients eligible for enrollment. The state currently receives a report from CDC with DSME enrollment data, but the report does not distinguish enrollment by diabetes type (Type 1, Type 2, gestational, childhood, or prediabetes).

The Washington panelist is interested in using the APCD to investigate enrollment in programs and services, which will help to understand reporting and utilization among different coverage groups. Additionally, Washington would like to look at enrollment in the National Diabetes Prevention Program (DPP) relative to the proportion of patients with prediabetes.

APCDs also hold promise to inform surveillance of chronic disease expenditures. Epidemiologists can use expenditure data to describe the burden of a disease and underscore the potential value, including cost savings, of public health measures that prevent, identify, or intervene early in a disease course. The Rhode Island panelist has identified several ways she can use this longitudinal aspect of APCDs to understand the impact of cardiovascular disease and diabetes on her state, including the financial burden of healthcare and receipt of appropriate services.

The Hawaii panelist plans to examine the cost savings associated with participation in the National Diabetes Prevention Program (NDPP). She intends to look at variables such as costs of diabetes management in the outpatient setting, and those linked to ER/inpatient care for persons with diabetes, including those with complications, and use this data to project potential costs saved as a result of implementing the NDPP in Hawaii. Having such data could strengthen the case for coverage and reimbursement of the National DPP by payers, and increase availability and utilization of the program for residents.

Furthermore, the pharmacy data in APCDs can be used for estimating medication adherence for patients with hypertension or diabetes. Since 2013, CDC has required 1305 grantees to estimate medication adherence rates for antihypertensive and diabetic medications. These performance measures have been especially challenging for health departments to estimate as few states had statewide data sources for medication adherence at the inception of the grant. Other complications in estimating medication adherence have included: lack of statewide representative data, costs of accessing data, and complicated analyses.

All panelists expressed an interest in using APCDs for these measures. The Vermont panelist was interested in exploring with program staff the use of medication adherence data to help primary care practices engage in quality improvement. The Washington panelist has shared CDC guidance on

calculating medication adherence with the claims data analysts and managers participating in their Cross Agency Healthcare Data Workgroup.

Some panelists believe that APCD data could help to refine estimates of disease prevalence. The Minnesota panelist hopes to use the APCD to determine the extent to which diabetes may be underreported in hospital discharge data. The Washington panelist would like to investigate if the APCD can be used to estimate prevalence and the number of patients with prediabetes across different coverage groups because self-reporting on statewide surveys is low. Since APCD data are geocoded, the Hawaii panelist would like to conduct spatial analyses and map data by census tract. This would enable her program to understand nuances of prevalence, for example, the control rate and/or severity of illness and then would allow her program to look at factors such as complications and costs by geographic area.

Due to concerns that APCDs are less valid than other data sources in estimating statewide prevalence, APCD data can be compared with Health Information Exchange (HIE), hospitalization, and other data sources. While the panelists expressed confidence in the ability of their APCDs to serve as important data sources for cardiovascular and diabetes surveillance, they also noted that states considering APCDs should be aware of common limitations with these databases.

What are the challenges associated with using APCDs for surveillance of cardiovascular disease and diabetes?

While the limitations discussed on the conference call were not exhaustive, several themes stood out: 1) APCDs do not fully represent the statewide population; 2) APCDs do not traditionally contain clinical laboratory, biometric or EHR data; and 3) APCDs require more complex analysis and different analytical skills than traditional cardiovascular and diabetes surveillance sources.

Representativeness of the State Population

The percentage of the state population covered by each APCD varies, which may affect how health departments can use their APCD data for understanding chronic disease burden. As noted above, APCDs can offer great benefit because they often include statewide data from multiple payers. However, they may not represent the full population participating in the healthcare system, especially people who are uninsured, self-pay, or are enrolled in a Department of Defense plan. This can make it difficult to

ascertain the population that is not included in an APCD. One of the more comprehensive APCDs, the Vermont APCD includes data for approximately 90 percent of state residents covered by commercial insurers and 100 percent of residents covered by Medicaid and Medicare.

However, the Vermont panelist notes that because the database does not include all residents, the data are best viewed as statewide estimates. The Maine APCD includes data on all residents covered by Medicaid and some residents covered by private insurers. Private insurers with less than \$2 million per calendar year of adjusted premiums or claims are not required to report to the Maine APCD. Furthermore, the Maine APCD includes all Medicare medical claims, but not all Medicare pharmacy claims, meaning that certain types of analyses may be more representative of the state population than other types of analyses.

It takes time to incorporate payers into the APCD data submission process. As an APCD develops, it may start with a few insurers and add more over time. For example, the Hawaii APCD was formally chartered by the Hawaii state legislature with provisions for mandatory contribution of data from Medicaid, Medicare, and state employee and retiree health plans. Due to considerations around *Gobeille v. Liberty Mutual*, private insurers may voluntarily submit data, but are not required to, thus the APCD represents a subset of the insured Hawaii population.

The Rhode Island panelist noted that even when a broad category of data are included in the APCD, there may be subgroups of the data that are distinct and need to be considered differently, such as Medicaid fee for service within the Medicaid dataset and self-insured plans within the commercial set.

Chronic disease epidemiologists are interested not only in statewide data, but also in disparities in care, quality, and cost by subpopulation. Even when the APCD includes a large proportion of the state population, conducting analyses of subpopulations may be challenging. While APCD data generally include patient age, sex, and geographic information, panelists reported difficulty analyzing data by race or ethnicity. Payers may not capture patient racial or ethnic information in claims as there are many ways race and ethnicity may be coded, or the ethnicity information available through claims may be unreliable for other reasons. Because national data indicate significant racial and ethnic disparities in cardiovascular disease and diabetes, epidemiologists can benefit greatly from higher quality data that helps them to understand how these patterns persist at the state and local levels.

Lack of Clinical EHR or Laboratory Data

One of the major gaps in cardiovascular and diabetes surveillance sources is data that can be used to understand primary care diagnoses and treatment. While claims data can illuminate this through data such as date of first diagnosis, procedure codes, and pharmacy claims, APCD data does not traditionally contain laboratory values, such as blood pressure or A1c readings, which could be useful in surveillance of disease severity and in tracking reductions in severity for a cohort of patients.

Additionally, a claim will only show a diagnosis of a disease if a health encounter is related to that disease. While this can potentially be overcome by looking back to see if an individual has had a claim for diabetes or cardiovascular disease in the last several years, some individuals may still be missed. The panelists recommend that epidemiologists work with APCD staff to understand the types of analyses that suit the data available.

Complexity of Analysis

Even though they have compelling value for chronic disease surveillance, APCDs are generally difficult for chronic disease epidemiologists to use. Several panelists commented that the skills required for claims data analysis are not commonly taught in public health or epidemiology graduate programs and are different from the skills needed to analyze traditional public health data sources, such as BRFSS, mortality, or hospital discharge databases. Panelists who have direct access to APCD data noted that analysis was time consuming and challenging. Having strong analytical skills is not enough; a thorough understanding of the dataset and its nuances--including reimbursement and enrollment among each participating payer and its coverage groups--is essential to correctly interpreting estimates provided by the APCD.

For example, with diabetes data, estimates for all coverage groups combined may be misleadingly low and overshadow higher estimates in specific coverage groups. Epidemiologists also need significant amounts of dedicated time to learn the datasets and conduct analyses; many cardiovascular and diabetes epidemiologists have hybrid roles as evaluators, data managers, or more general public health capacities. Similarly, panelists who worked with third party analysts to query data noted the need to establish a common vernacular with the analysts, who often do not have backgrounds in public health or epidemiology.

Changing Policies Related to APCD Reporting

Federal policy is having a large impact on state APCDs. Following the *Gobeille* Supreme Court decision, the US Department of Labor has debated on how to gather information from self-insured payers that will have a big influence on requirements to submit to the APCD. Having this additional information will help with the coverage of state APCDs. Additionally, the Substance Abuse and Mental Health Services Administration (SAMHSA) CFR Part 2 affects reporting of substance abuse data. Each state APCD is grappling with how to get insurers to submit substance use treatment data. This has implications for chronic disease data and hypertension and diabetes because some insurers are redacting claims data from primary care visits that contain codes related to substance use. SAMHSA intends to release sub-regulatory guidance for APCDs, but the timeline for this is unknown.

What organizational structures, policies, or processes can facilitate success for chronic disease programs interested in using APCDs to augment their surveillance systems?

The panelists suggest several considerations for health departments in planning to access and use APCDs for cardiovascular disease and diabetes surveillance. NACDD notes that these considerations apply to epidemiologists interested in accessing and using APCDs for other chronic disease areas.

Direct Access to APCD Data

Panelists with direct access to APCD data expressed fewer issues navigating organizational structures and processes to use data than those that accessed or anticipated accessing the data through third parties. The Rhode Island panelist is able to access deidentified data and all analytic capacities of the APCD. Although the Vermont APCD is managed by a third-party contractor, the Vermont panelist has complete access to commercial and Medicaid claims data, and the health department is putting pieces in place to access Medicare data from the APCD.

Data Use Agreements and Purchases

Among the six states represented on the call, four had APCDs that were external to the health department. For health departments with external APCDs, data use agreements are standard practice. The data use agreement for Maine addresses data storage, such as how and where data are stored; the length of time the data will be used; and intended research goals. For the Washington APCD, which will be launching in early 2018, the system is

required by law to be self-sustaining. Users will need to purchase a license for access to a data enclave or an extract of the data.

Training on APCDs

The panelists noted that training is a recommended prerequisite for yielding benefit for epidemiologists analyzing and interpreting APCD data directly as well as those working with third parties to conduct the analyses. Each participating payer and their coverage groups have different backgrounds and nuances related to enrollment and reimbursement, which affects their data collection and reporting. Epidemiologists working directly with the data can benefit from training on claims data and training specific to the dataset. Those working with third party analysts can benefit from learning about the dataset contents, variables, and coding, as well as training on types of analyses and reporting are appropriate and feasible for claims data analysis, which will help them develop good data requests.

Panelists see a role for CDC to partner with states on exploring what APCDs can do to improve surveillance. In addition, CDC can help to point states to resources to support training of epidemiologists on APCD use or use of other types of complex claims data. National organizations such as NACDD could assist with promoting peer-to-peer exchange on APCDs, establishing standard definitions, codes, or analysis methods that can be shared across states.

Support for Cardiovascular and Diabetes Use Cases

The panelists from Hawaii and Washington mentioned the importance of building support with key administrators for their data analyses. Both anticipated their APCDs to start operations in Summer/Fall 2017 and invested in developing relationships that would help to prioritize their data requests among the many that would compete as initial “use-cases” for their APCDs. One of the core research steps in implementing an APCD is setting an iterative approach for expectations and claims data use-cases development, to steadily build accomplishable research priorities.

The Washington panelist has monthly coordination meetings with analysts from the state Office of Financial Management, which oversees the APCD, to keep apprised of activities that affect both agencies. The Washington Department of Health also has a representative on one of the advisory panels for the Washington APCD. The Hawaii panelist has ongoing conversations with the ACPD team, state Medicaid agency, and with the state health commissioner to gain support for the value that diabetes-related queries could provide to both the health department and other stakeholders.

Incorporation of APCD Costs into Surveillance Budgets

While none of the panelists reported paying for APCD data, at least two anticipated needing to pay for such data in the future. State legislators and senior health department administrators may be best positioned to influence fees for state health department programs to access APCD data. The 1305 grant did not require or recommend a specific percentage of state budgets to be dedicated to surveillance, but such a recommendation could liberate some grant resources to assist with APCD access fees and analysis costs.

Conclusions

APCDs present both opportunities and challenges to state public health programs addressing cardiovascular disease and diabetes as part of CDC grants. Obtaining healthcare data from multiple payers promises to augment existing chronic disease surveillance systems with information on health status, healthcare costs, and utilization, all of which can illuminate different aspects of disease burden than traditional surveillance sources can. However, accessing the data, developing and refining research questions, and interpreting the results may require a level of support from data stewards and gatekeepers that is higher than that needed for traditional data sources. As noted by the presenters on the conference call, chronic disease epidemiologists look to national organizations such as CDC and NACDD to help them identify best practices and models for using APCDs in surveillance and to facilitate exchange of APCD resources and information for chronic disease prevention programs.

Due to its focus on an evolving topic, the conference call discussion described in this issue report represents a snapshot in time. The state health department context for accessing and using APCD data is constantly changing for diabetes and hypertension programs, particularly as databases and the structures and procedures for accessing them mature. Surveillance priorities for cardiovascular disease and diabetes are heavily influenced by required performance measures and strategies for federally funded prevention programs at the state level.

States are looking to CDC to see what these will be as the 1305 grant concludes and new federal funding becomes available in 2018. Also changing is the national context for encouraging payers to contribute data to APCDs; legal decisions such as *Gobeille v. Liberty Mutual* can have widespread implications for public health use of APCDs. The states featured in this issue

report are monitoring these changes and constantly looking for ways they can leverage the benefits of APCDs as part of their surveillance programs.

Resources

- Bartoloini, E., and Paradis, R., *All Payer Claims Databases: Unlocking the Potential*, December 2014. Available at <https://www.apcdouncil.org/publication/all-payer-claims-databases-unlocking-potential>
- Council of State and Territorial Epidemiologists. *Chronic Disease Epidemiologist Orientation Manual: A Resource for Applied Epidemiologists*. Atlanta, GA: CSTE; 2015. Available at: <http://www.cste2.org/Publications/CSTE%20Chronic%20Disease%20Epidemiologist%20Orientation%20Manual-A%20Resource%20For%20Applied%20Epidemiologists.pdf>
- *State of Hawaii Act 139, which charters the APCD as a collaborative partnership of the state and university*: http://www.capitol.hawaii.gov/session2016/bills/GM1241_.PDF
- *Key Regulatory Issues Facing APCD States Post "Gobeille v. Liberty Mutual"*, APCD Council and the National Academy for State Health Policy (NASHP), April 2016. Available at <https://www.apcdouncil.org/publication/key-regulatory-issues-facing-apcd-states-post-gobeille-v-liberty-mutual>
- Robert Wood Johnson Foundation. *The Basics of All-Payer Claims Databases: A Primer for States*. Princeton, NJ: RWJF; 2014. Available at: <http://www.rwjf.org/en/library/research/2014/01/the-basics-of-all-payer-claims-databases--a-primer-for-states.html>.
- Rosenthal, E. "Those indecipherable medical bills? They're one reason health care costs so much." *New York Times*, March 29, 2017. Available at: https://www.nytimes.com/2017/03/29/magazine/those-indecipherable-medical-bills-theyre-one-reason-health-care-costs-so-much.html?rref=collection%2Fsectioncollection%2Fhealth&action=click&contentCollection=health®ion=stream&module=stream_unit&version=latest&contentPlacement=4&pgtype=sectionfront&r=0
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Appendix A

Access to APCD Data Among Featured State Health Departments

	Status of Access to APCD Data for 1305 Programs*	Participating Health Plans	APCD Stewardship Internal or External to DOH?	State 1305 Epidemiology and Surveillance Contacts
Hawaii	Planned	Medicaid, Medicare, state employee/retiree health plans	External	Ranjani Starr ranjani.starr@doh.hawaii.gov
Maine	Active	Commercial (included, but plans are not required to report), Medicaid	External	Caitlin Pizzonia caitlin.pizzonia@maine.gov Pamela Albert pamela.f.albert@maine.gov
Minnesota	Active	Medicaid, Medicare, Commercial, Self-insured (voluntary)	Internal	Renee Kidney renee.kidney@state.mn.us
Rhode Island	Active	Medicaid, Medicare, Commercial	Combination	Dora Dumont dora.dumont@health.ri.gov
Vermont	Active	Commercial, complete Medicaid and Medicare	External	Paul Meddaugh paul.meddaugh@vermont.gov
Washington	Planned	Medicaid and commercial	External	Angela Kemple angela.kemple@doh.wa.gov

*All states with "planned" access anticipated access to be available in Fall 2017

Appendix B

Legal Considerations for State Health Departments in the Wake of Gobeille v. Liberty Mutual

As mentioned above, discussion of the implications of the *Gobeille* decision on APCDs is expanded in the CDC Public Health Law Program's Issue Brief, *Public Health Law and APCDs: Gobeille v. Liberty Mutual*. Because APCD data collection varies from state to state, NACDD and CDC advise CDC-funded diabetes and hypertension programs to meet with their health department legal offices and determine how the law could affect an APCD in their state. Suggested questions are below.

For states with APCDs:

- Does my state have legal requirements for reporting all-payer claims data? How does this information flow right now?
- Do our state law requirements conflict with the Supreme Court decision this year in *Gobielle v. Liberty Mutual Ins. Co.*? Which parts of our state laws on this topic continue to be effective?
- Do we have plans to revise our current APCD provisions? If so, as someone who could potentially use this data toward public health goals, can I take part in those decisions?

For states without APCDs:

- Are there ways that our state laws now support our public health department getting access to all-payer claims data?
- If we want to create an APCD to support our public health work, given the decision in *Gobielle v. Liberty Mutual Ins. Co.*, should we pursue changes to state law or policy?
- However we set up an APCD in our state, what are the current legal implications and related considerations we should take into account?

In addition to contacting their legal representative, health departments may reach out to [CDC's Public Health Law Program](#) for consultation. A technical assistance request form is [available here](#).