

**NCVHS Hearing on Claims-based Databases for Policy and Evaluation**  
**Summary of Testimony**  
**June 17, 2016**

Capital Hilton Hotel  
1001 16th Street, NW, Federal A Room  
Washington, DC 20036

The National Committee on Vital and Health Statistics (NCVHS) convened a hearing “Claims-Based Databases for Policy Development and Evaluation: Overview and Emerging Issues,” on June 17, 2016. The meeting was open to the public and was broadcast live on the internet. A link to the transcript also is available on the NCVHS website.

**NCVHS Leadership**

Walter G. Suarez, M.D., M.P.H., Chair  
James Scanlon, HHS Executive Staff Director  
Rebecca Hines, MHS, Executive Secretary

**Committee Members**

Raj Chanderraj, M.D., F.A.C.C.  
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Llewellyn J. Cornelius, Ph.D., LCSW  
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Robert L. Phillips, Jr., M.D., MSPH  
Helga E. Rippen, M.D., Ph.D., M.P.H., FACPM  
William W. Stead, M.D. (phone)

**Absent Members**

Barbara J. Evans, Ph.D., J.K., LL.M., Co-Chair  
Richard W. Landen, M.P.H., M.B.A.  
David A. Ross, Sc.D.  
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**Staff**

Debbie M. Jackson, M.A., NCHS  
Katherine D. Jones, M.S., NCHS

**Appendix A provides the hearing agenda and list of presenters.**

## Others in Attendance

Karynlee Harrington, Maine Health Data Organization  
Gail S. Kocher, M.P.A., Blue Cross/Blue Shield  
Margaret Weiker, NCPDP, Director, Standards Development  
Omoniyi Adekanmbi, CAQH  
Sheryl A. Turney, M.Ed, PMP, HealthCore

## Hearing Overview

On June 17, 2016, the National Committee on Vital and Health Statistics (NCVHS) held a hearing "*Claims-based Databases for Policy Development and Evaluation*," to gather information and receive input from stakeholders regarding the key issues related to the current state of development, challenges, issues and opportunities presented by the increasing size, number and use of claims-based databases in the United States.

All Payor Claims Databases were a focus of the 2016 NCVHS workplan, a focus supported in a February 11, 2016 letter from America's Health Insurance Plans (AHIP). This hearing was convened to gather input from key stakeholders in order to begin framing concerns and opportunities.

This hearing summary is a report of testimony provided to the Committee and serves as a snapshot of rapidly changing data resources and data uses. This summary is intended to extend the public-private dialogue about how claims-based database resources should be supported at the state and federal levels and how they will evolve as health data resources continue to expand. The Committee is aware that considerable activity has taken place since this hearing was held; thus this summary excludes information regarding relevant activity that has occurred since the June 2016 hearing.

The **objectives of the hearing** were to understand:

- Current status of Claims-based Databases, including APCDs, what's driving their development, and common challenges states and other developers must address.
- Public benefits and concerns for consumers, policy makers, researchers and population health programs.
- Business model benefits and concerns for providers, payers and state/federal programs.
- Technical challenges encountered in reporting that diminish the value of these databases.
- Role of Claims-based Databases in a health care system undergoing reform: Accountable Care Organizations (ACOs), Primary Care Medical Homes Demonstration Projects (PCMH)s, Medicare Access & CHIP Reauthorization Act of 2015 (MACRA) and its Merit-Based Incentive Payment System and (MIPS) and Alternative Payment Models (APMs).
- Emerging reporting needs to support healthcare transformation and payment reform, e.g., capturing non-claim transactions, data linkage, etc.
- Review of formats and opportunities to standardize reporting formats across states (X12, NCPDP and others).
- Benefits, efficiencies, and barriers to the adoption of a common Claims-based Database and APCD reporting standard.

- Federal roles and opportunities to advance, improve claim-based databases and APCD development in states.
- An outline for a roadmap for achieving greater standardization and the role that NCVHS could play in supporting the development of such a roadmap.

The **agenda was organized into three areas** (see Appendix 1 for agenda and speakers):

- I. Policy and Reporting Issues:
  - Value, Purpose, Structure, Public Reporting and Policy Considerations
  - Data Suppliers and Users
- II. Federal and State Issues
- III. Standards: Background, Emerging Issues and Challenges

**Testifiers** included representatives from:

- States invested in the development of claims-based databases
- Health Plan Representatives
- ACOs
- Employer Representatives
- Federal agencies, i.e., Centers for Medicare & Medicaid Services/Medicaid, ONC, VA, OPM
- Researchers
- APCD Council

### **Background on Claims-based Databases, including All-payer Claims Databases (APCDs)**

There is broad industry agreement about the need for improvement in the value of health care to achieve the Triple Aim of better health, better quality, and lower costs. State and federal policy makers are seeking options for controlling escalating costs through payment and health care reform policies, and thus have been seeking data to inform these efforts.

Because of their broad availability, claims administrative data sources are being utilized by a range of audiences for a range of purposes. Since the first statewide APCD system was established in Maine in 2003, state interest in and experiences with APCD systems have been growing. The most common type is the All-payer Claims Database (APCD). The APCD Council lists 19 states as having enacted such laws and/or regulations, and it further lists all but 8 states have some level of effort around creating an APCD (<https://www.apcdouncil.org/standards>). A 2014 issue brief developed with support from the Robert Wood Johnson Foundation succinctly defines the essential elements and key historical highlights of APCD developments ([http://www.rwjf.org/content/dam/farm/reports/issue\\_briefs/2014/rwjf409989](http://www.rwjf.org/content/dam/farm/reports/issue_briefs/2014/rwjf409989)):

- APCDs are large-scale databases that systematically collect medical claims, pharmacy claims, dental claims (typically, but not always), and eligibility and provider files from private and public payers.
- APCDs are based on the existing claims transaction platforms used by providers and payers.

- Most of the statewide APCDs established in the last 10 years are mandatory reporting initiatives, governed by statute and regulations.
- APCDs are becoming a core health data set in many states, much like hospital discharge data reporting systems and vital statistics.

## **Summary of Testimony**

After a day of hearing testimony from 21 testifiers, with additional information provided in writing from organizations unable to attend, the Committee reflected on the input provided.

Committee members observed that APCDs and similar claims-based databases are part of a fast-changing, evolving landscape. Any federal involvement, guidance, or recommendations would need to take this into account.

With the wide range of stakeholders and perspectives offered, the Committee observed distinct goals and motivations for investment in APCDs and a potential collision of interests and investments. In general, testifiers from states, policymakers, purchasers and researchers presented favorable assessments of the potential for claims-based databases to provide valuable and actionable information. On the other hand, testimony from industry representatives tended to question the value and utility of the data that make up these systems, emphasizing limitations of the data combined with the attendant costs and resources involved in their development and maintenance. This group is generally looking for standardization and consideration of distributed models rather than centralized models.

To follow is a summary of the testimony provided, with sources noted as appropriate. The summary is organized into the following topic areas:

- A. Benefits and Value – Users and Uses
- B. Governance and Structure – Funding and Sustainability
- C. Access to APCD Data/Data Release Policies
- D. Integration of Data Sources: Claims and Clinical Data
- E. Delivery System Reform & Payment System Reform: Implications
- F. Claims Data, Data Quality and Data Limits (ERISA)
- G. Data Privacy/Security & Cybersecurity Issues
- H. Standards: Data & Electronic Exchange
- I. Federal role: Medicare, OPM, DOL, others
- J. Potential Future Considerations

Selections and quotes were chosen to provide a balance of perspectives offered by panelists and those who provided written testimony.

### **A. Benefits and Value – Users & Uses**

- i. The goals that have been communicated and socialized are to use the APCD data to achieve the triple aim of reducing the cost of health care, increasing the quality of health care delivered, and increasing the accessibility to health care services within a specific state or region. However, in our experience the specific approaches, metrics, and data analysis for measuring progress against these objectives are not well defined. (Anthem, Inc.)

- ii. Some states have used APCD claims data to develop websites which seek to provide cost data for common procedures. These websites often allow residents to compare procedure costs by geographic area or healthcare entity (e.g., across hospitals). Many states also make data available to third parties for research. Data requests go through a process to determine if the data requester meets requirements established by the APCD entity for data stewardship and data use. The data elements available and the data governance process for these data requests differ from state to state. Some states publish all requests for data as well as a summary of the data use, the outcome of the request, and the contact information for the data requestor; others do not. Many of the APCD claims based databases charge a fee for access to the APCD claims data to help defray the cost of maintaining the databases. (Anthem, Inc.)
- iii. Policy makers see data as a public good and APCDs as an important foundation to work from. More needs to be done to make APCD data easier to access and use – comprehensively bringing different data sets together, from payers and providers, and inclusive of community services and resources. It's only then that we will be able to be data driven in improving the health outcomes of individuals, for populations, and ensure value, both cost and quality. (New Hampshire DHHS)
- iv. APCDs are an important tool for helping consumers choose providers based on cost and quality. The Virginia health department is using the APCD to understand the burden of diseases such as diabetes and heart disease. APCD information is also supporting efforts to address the horrific increase in deaths from opioid addiction and the many issues related to behavioral health access and treatment. (Virginia Health Information)
- v. Significant growth in APCDs has occurred in the last several years for several reasons:
  - States want to better understand and manage the cost and quality of health care delivered within their borders and establishing an APCD is seen as enabling them to do so. As use of APCDs has grown across states, some have expressed concerns that some states have pursued databases costing millions in state funds and unanticipated costs and burden for health plans, without a clear understanding of how to best use the data. Intended use cases vary by state.
  - A second and rather significant reason for the growth of APCDs, especially in recent years, relates to the availability of federal funding. While many states rely on general state appropriations and industry fee assessments for the ongoing operations of their APCDs, many have also used federal funding sources, particularly for the start-up costs to establish APCDs.
  - The Affordable Care Act also provided funding for APCD development if the APCD is linked to payment reforms. Millions of dollars in State Innovation Model or SIM grants have been and will continue to be given to support state efforts to develop and test state-led, multi-payer health care payment and delivery system reform. It is this last funding source, in particular, that has contributed most recently to the growth of state-based APCDs without any common criteria or guidance for how such databases should be constructed.
  - A fourth likely reason for the growth of APCDs is the national movement toward value-based payment models that has focused attention on the critical role that data play in assessing quality and cost. More specifically, in a value-based system, providers are

taking on additional financial risk for the patients they care for, so accurate and meaningful clinical data is essential. To that end, electronic health record data (EHR), clinical registry data and data exchanged by the multiple providers caring for a patient offer the most useful and actionable data for physicians at the point of care. (America's Health Insurance Plans)

- vi. The APCD in Massachusetts supports analysis and research related to the impact of health care reform initiatives, such as:
  - Understanding trends in health plan coverage for Massachusetts residents.
  - Understanding trends in both plan paid and patient out-of-pocket costs by commercial insurance products and Medicaid delivery systems and programs.
  - Understanding trends related to utilization, quality and access to health care services in Massachusetts.
  - Understanding price variation by payer, products, regions, etc.
  - Understanding how ACOs, PCMHs, etc. affect cost, quality and access to health services across payers, health systems and populations in Massachusetts.
  - The encrypted Master Patient Index allows APCD data users to track Massachusetts residents across payers and health insurance products (e.g., analyze health plan migration patterns of residents as they move between plans and insurance products). (Massachusetts Center of Health Information and Analysis)
  
- vii. In 2007, the New Hampshire Insurance Department was the first in the nation to implement a consumer accessible HealthCost website, which draws from the APCD. It incorporates quality data to better compare providers and plans on both cost and quality. This moves closer to understanding the value of health services and enabling consumer choice based on value. (<http://nhhealthcost.nh.gov/>) (New Hampshire DHHS)
  
- viii. The Office of Personnel Management is a very large purchaser of health services and is interested in analyzing health claims information to better inform its contracting with health plans around cost, access and quality and to improve the overall health of the covered population through its wellness and preventive services work with federal agencies and organizations representing retirees. OPM published two Systems of Records Notices to address the establishment of its health claims data warehouse. OPM has built the necessary systems; our next step is to populate the data warehouse with health plan data. (Office of Personnel Management)
  
- ix. From a Centers for Medicare & Medicaid Services oversight perspective, Medicaid participation in APCDs is not required. States can choose to participate and share their Medicaid claims/encounter data if they determine that doing so would address business needs such as access to all payer data for planning needs related to cost, efficiency, quality of care, system utilization, patterns of care, and geographic differences. In some cases, it is the state itself that hosts the APCD, which dramatically increases the likelihood of Medicaid participation (ex. Utah, Kansas or Tennessee). There are some excellent examples of how states have used the data in APCDs to pinpoint key issues at: [https://www.apcdshowcase.org/case-studies?field\\_category\\_tid=7](https://www.apcdshowcase.org/case-studies?field_category_tid=7) (Centers for Medicare & Medicaid Services)

- x. The Pittsburgh Business Group on Health stated that APCDs offer employer access to information important for exercising their fiduciary duty under ERISA. They brought together the region's leading employers to set performance expectations of cost and quality with the providers and health plans in the region, and to inform each employer of how to improve their own benefit offerings to their employees. They found that employers support any tool that allows them to put their data to work for their employees. They use the data to: 1) increase transparency about quality, cost, and value; 2) to evaluate comparative effectiveness of health systems and clinics for high-cost patients and to implement two-sided risk for providers; and, 3) drive improvement and cost containment. (Pittsburgh Business Group on Health)
  
- xi. The Pacific Business Group on Health houses the California Performance Information System, the largest multi-payor claims database (MPCD), covering 12 million people (including Medicare). PBGH says that private employers and public purchasers value APCDs and MPCDs in four ways: 1) they offer neutral, third party information on the quality, cost, and resource use of providers; 2) they are an important resource for purchasers engaging in alternative payment models; 3) they provide independent information to purchasers on quality, cost, and resource use for global payment methodologies and gives purchasers confidence that these types of models are paying for value; and, 4) these databases can also stimulate the healthcare market as public transparency motivates provider improvement and enables consumer choice. Several state-based examples were offered for each of these points. (Pacific Business Group on Health)

## **B. Governance and Structure – Funding and Sustainability**

- i. In some states an independent state agency is created through legislative mandate and funded through assessments of hospitals, ambulatory surgical centers and payer surcharges. For example:
  - The Maryland Health Care Commission is funded through a \$12 million assessment on hospitals, health insurers and HMOs, health care professionals, and nursing homes. Assured funding has provided predictability in making investments in the Maryland APCD. The APCD competes with multiple priorities at the Commission, including efforts to advance primary care, diffuse health information technology, traditional state health planning functions, and quality measurement and reporting efforts. (Maryland Health Care Commission)
  - In 2003, the New Hampshire legislature enacted NH RSA 420-G:11-a, creating a health claims database as part of the state's insurance Code. Our database has provided the state with critical information about the health of its citizens and contributed to our understanding of health care utilization, cost, and quality. (New Hampshire, DHHS)
  
- ii. Federal funding for Medicaid participation in an APCD is variable based upon how it is used by the Medicaid program. Centers for Medicare & Medicaid Services works with each state Medicaid agency individually on their proposal and request for matching funds. (Centers for Medicare & Medicaid Services)

- iii. Distributed or federated models provide a proven alternative to centralized data collection that can work around the legal issues and uncertainties arising from *Gobeille*.<sup>1</sup> A distributed network can perform essentially all the functions desired of a centralized database, while avoiding many disadvantages of centralized databases:
  - They allow data holder to maintain physical control over their data.
  - They ensure ongoing participation of individuals who are knowledgeable about the systems and practices that underlie each data holder's data.
  - They allow data holders to assess and authorize query requests, or categories of requests, on a user-by-user or case-by-case basis.
  - Distributed systems minimize the need to disclose protected health information thus mitigating privacy concerns, many of which are regulated by the Privacy and Security Rules of HIPAA.
  - Distributed systems minimize the need to disclose and lose control of proprietary data.
  - A distributed approach eliminates the need to create, secure, maintain, and manage access to a complex, central data warehouse.
  - A distributed network also avoids the need to repeatedly transfer and pool data to maintain a current database, which is a costly undertaking each time updating is necessary. (Blue Cross Blue Shield Association)
- iv. Each state where Anthem, Inc., submits APCD data modifications are needed to the data submission requirements at least annually, and many APCD data collection entities attempt to update their data more frequently—at times with significant push-back from the payer community. The frequency of the changes alone demonstrates a lack of clarity or specificity with respect to the data being requested and how those data will be used. For example, data on race, ethnicity, social security numbers, and temporary residence locations (particularly for students) are often required elements that are not universally populated in claims data. (Anthem, Inc.)
- v. Significant implementation issues: limited populations included (not representative); differences between fee-for-service and capitated; lack of identifiers; limitations of claims-based data; differences across states. (Anthem, Inc.)
- vi. The Pittsburgh Business Group on Health acknowledges that overcoming obstacles to APCDs requires: 1) Alignment of interest among employers and organizations to manage and deliver benefits; 2) Collaboration across employers, providers, health plans, and advisors to jointly discuss best practices and actionable priorities based on factual data; and resolving data-blocking by third-party administrators and health plans. (Pittsburgh Business Group on Health)

### **C. Access to APCD Data/Data Release Policies**

- i. Few testifiers focused on specific details of data release policies, with the state of Maryland as a notable exception:
  - The Maryland Health Care Commission (MHCC) releases detailed data from the APCD consistent with HIPAA regulations and State law, and following approval by the full

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<sup>1</sup> See Section F.1. below for a description of the *Gobeille* case.



Commission. About two years ago, MHCC established an expanded data release program modeled after Centers for Medicare & Medicaid Services' approach for releasing Medicare data through the Research Data Assistance Center (ResDAC.) An entity seeking APCD data must describe the planned use of the data, document need for specific sensitive data elements, develop a data management plan, and obtain approval from the MHCC Independent Review Board (IRB) or another IRB recognized by MHCC. MHCC has released data through this process to researchers: studying access to health care services on Maryland's Eastern Shore; evaluating the new global payment model contract on behalf of Centers for Medicare & Medicaid Services; and evaluating the patient-centered medical home (PCMH) program for a major carrier in the state. (Maryland Health Care Commission)

- MHCC is examining additional data release strategies, including allowing access on a subscription basis to users that can demonstrate ongoing need for the current data sources. (Maryland Health Care Commission)

- ii. Understanding the extremely sensitive nature of the data in the system, OPM has taken additional precautions (and time) to design the safest and most secure system possible protecting personal health information based on the latest technical safeguards available. (Office of Personnel Management)

#### **D. Integration of Data Sources: Claims and Clinical Data**

- i. Many Health Information Exchanges organizations (HIEs) are also now requesting the submission of claims data to be combined with clinical data for reporting, analysis and resale to third parties. These HIE data repositories each come with unique requirements. (Anthem, Inc.)
- ii. [America's Health Insurance Plans] endorse the adoption of a common framework and approach for data collection and use. In so doing, NCVHS can support health plan and other stakeholder efforts to provide consumers with actionable data as well as inform state efforts to understand health care cost and utilization trends. Moreover, due to the limited nature of APCDs as claims databases, they can be used in conjunction with clinical data sources to provide a more meaningful and complete view of health care quality, cost, and value as we move toward a more value-based health care system. (America's Health Insurance Plans)
- iii. Over the next several years, Maryland stakeholders hope to link the APCD with clinically meaningful electronic health records and registry data accessible through the MHCC-designated statewide health information exchange. (Maryland Health Care Commission)
- iv. Greater access to data on the social determinants of health, and the barriers and resources available to improve outcomes, is needed: We are likely all familiar with the drivers of health being primarily our social circumstances, behavioral patterns, and our environment – those data need to be captured and made actionable. (New Hampshire DHHS)
- v. Capturing and Using Data on the Social Determinants of Health: In a public-private partnership, New Hampshire Medicaid is working with the Blue Cross/Blue Shield Association to present an easy to navigate website that integrates clinical data with social determinants of health data,

allowing for augmented case management for targeted populations. The website, when complete later this summer, will identify community assets and innovations, at a granular level, so that health practitioners, and local and regional stakeholders can affect change in their neighborhoods. NH would have been hard pressed to develop this resource on our own as the BC/BS Association integrated over 21 different data set, some public, others purchased, including Google data on traffic – to generate drive times, NIH data on alcohol consumption, US Department of Agriculture data on grocery stores and grocery store bar code scans to look at consumption of fruits and vegetables, US geological land survey data to see where sidewalks exist, HRSA and SAMHSA data to look at primary care and mental health clinics, among others. [New Hampshire DHHS] will layer in data about the NH Medicaid population and augment the website with various community and other programs so that the user will be able to see both where there are opportunities and resources in an intuitive and elegant Google maps interface at a remarkably detailed level. (New Hampshire DHHS)

- vi. There are two areas that may limit the value of APCDs for the Medicaid Program. The first is that many states desire the layering of clinical data and claims data to have a more fulsome view of both the utilization, cost and impact of Medicaid coverage. In many cases, states may find participation in an APCD to only answer some of their questions and have to also work with health information exchange entities for the clinical data to complete the picture. That can cause operational inefficiencies and obstacles with person matching, link keys, etc. If it is not already occurring, expanding the vision of APCDs to include functional linkages to health information exchange with proper privacy protections would perhaps obfuscate the need for state Medicaid Programs to build their own separate data pathways. Secondly, the Medicaid and CHIP programs in most states are integrated with human services programs such as SNAP and TANF. Understanding just healthcare services utilization underestimates the social determinants of healthcare utilization, cost and outcomes. Many states have a vision to better understand how their common beneficiaries in these programs are accessing services, defining “provider” in a much more expansive manner and adopting a data analytic approach that is no longer exclusive to healthcare claims. (Centers for Medicare & Medicaid Services)
- vii. Pacific Business Group on Health called for four specific issues for improving the utility of APCDs (and MPCDs) for purchasers: 1) generate results on a named provider basis, notably physicians, practice sites, and facilities; 2) include cost information; 3) seek purchasers and business coalitions as stakeholders; and 4) collaborate to bring together claims, clinical, and patient-reported data. (Pacific Business Group on Health)

## **E. Delivery System Reform & Payment System Reform: Implications**

- i. Although there are ongoing challenges with supporting and maintaining the MA APCD, it is the only data set that fully supports researchers, policy makers, state agencies, and other APCD users in understanding the impact of health care reforms in terms of health care coverage (public and private), utilization, cost and quality of health care services provided to Massachusetts residents. (Massachusetts Center of Health Information and Analysis)
- ii. The State of Maine’s APCD is one of the essential components needed to support and advance a wide range of health reform efforts—as measurement should be the baseline for all delivery

system and payment reform efforts. The needs of the broad group of data users will continually evolve especially as new delivery and payment models are developed and tested. (Maine Health Data Organization)

- iii. Like many health departments, the Virginia Department of Health has a key role in understanding the health of Virginians, conducting programs to improve access to care and reducing disparities while being a good steward of funds needed to accomplish these goals. Comprehensive All Payer Claims Databases are an important tool. Health systems and payers need comprehensive information in Accountable Care Organizations. Consumers and businesses need information on cost and quality given rising costs and more cost sharing by consumers. (Virginia Health Information)
- iv. The new Medicare Access and CHIP Reauthorization Act of 2015 (MACRA) provider payment rules define the need for Centers for Medicare & Medicaid Services to collect significant amounts of commercial claims from data submitters in order to support and inform the quality and cost initiatives under the new rules. At this time, no requirements or standards have been defined for the process or rules by which these data will be collected. (Anthem, Inc.)
- v. Most current APCDs currently do not support the variable payment models which increasingly seek to pay providers based on outcomes, quality and episodes of care rather than on claims or discrete encounters. As these new payment models are defined, data requirements for reporting against quality, cost and accessibility measures are growing. The current APCDs and claims databases must be completely retrofitted to accommodate the data requirements these new payment and quality models currently being refined under MACRA. (Anthem, Inc.)
- vi. The recent decision of the *Gobeille v. Liberty Mutual Insurance Company* case severely impacted the breadth and depth of claims-based data that will be included in the state APCDs moving forward – further eroding the potential for APCD data to be effectively used in assessing population health and cost trends when developing alternative payment models. (Anthem, Inc.)

#### **F. Claims Data and Quality – and Data Limits (e.g., ERISA and 42 CFR Part II)**

- i. There is a lack of consistency among APCD state entities with regard to what entities are required to submit claims data. [sic] The inclusion/exclusion rules have been impacted by *Gobeille v. Liberty Mutual Insurance Company* in which the U.S. Supreme Court held that ERISA preempted a Vermont state law that required ERISA employer groups (self-insured) to be data submitters to the Vermont APCD. (Anthem, Inc.)
- ii. For many of the state APCDs there is a process by which data extracts are submitted and go through a pre-process. Once this pre-process is completed (usually within a few days) the data go through a level of threshold checks and data quality checks. The APCD data may also go through an additional level of stratification or verification that results in questions from the state APCD entities to the payers - sometimes weeks, months, or years after the data were originally submitted. (Anthem, Inc.)

- iii. Even if centralized data are highly curated and extensively scrubbed – which [Blue Cross Blue Shield Association] believe is not the case for all current state APCDs – issues come up where it is essential to call on the people who produced the data, which is difficult to do when the data are centralized. Mark McClellan made this point when he commented on Centers for Medicare & Medicaid Services’ original proposal to centralize data for risk adjustment: relative to a distributed model, a third party’s centralized model that aggregates data across multiple payers is at a disadvantage in assuring data consistency and quality, because the data are removed from those who know them best and are thus best suited to assess and address any idiosyncrasies or anomalies. (Blue Cross Blue Shield Association)
- iv. In the short term, this (*Gobeille*) ruling undercuts a major rationale for states investing in APCDs: as *Gobeille* argued to the Supreme Court, “An all-payer claims database that omits self-insured plans cannot be considered accurate or comprehensive.” (Blue Cross Blue Shield Association)
- v. “The usefulness of an APCD depends on its comprehensiveness. . .” and “A database that included only claims from government payer programs, or even one that included claims from government payer programs and fully insured plans, would not be complete and therefore unable to approximate the health status of the American population as a whole. The population enrolled in self-funded insurance plans is a significant portion of health care users in this country and tends to be significantly younger and healthier than other populations....” (Blue Cross Blue Shield Association)
- vi. “If the 42 CFR Part II proposed rule is adopted without changes, it would likely present considerable challenges to high priority research and analytic agendas for the following reasons:
  - If payers exclude substance use disorder claims from the MA APCD, it would impede the ability of policy makers, researchers, payers, and providers to analyze and report on trends related to opioid abuse and treatment across payers and insurance products throughout Massachusetts.
  - Payers may use different algorithms to identify and/or exclude substance use disorder claims which would reduce standardization of the APCD medical and possibly pharmacy claims. For example, one payer may use the primary diagnosis to identify substance use disorder claims, while others may use a combination of primary and non-primary diagnoses, procedure codes, and national drug codes to identify or exclude claims, thereby creating issues when comparing measures of cost, utilization and quality across payers and service categories.” (Massachusetts Center of Health Information and Analysis)
- vii. The recent Supreme Court decision presents challenges to continued development of Maryland’s APCD. MHCC remains hopeful. The consensus-building initiatives that have already developed suggest that, with the federal government’s active participation, stakeholders can develop a solution that balances the information needs of multiple stakeholders with the protections afforded self-insured ERISA-protected private employers. (Maryland Health Care Commission)

- viii. Assessing, documenting and improving the quality of data that is submitted by the payers is extremely challenging. If you have experience managing, assessing, documenting and mitigating data quality issues at a single health plan, imagine the challenges of this effort across multiple payers and insurance products. This work is performed by CHIA staff and it is not outsourced to external vendors. (Massachusetts Center of Health Information and Analysis)
- ix. The biggest challenge to state operation of all-payer claims databases is the U.S. Supreme Court's March 1, 2016 decision in *Gobeille v. Liberty Mutual*, holding that federal law preempts Vermont's law requiring the submission of claims data with respect to self-funded employer coverage that is regulated by the U.S. Department of Labor under ERISA. The state of New Hampshire filed an amicus brief in *Gobeille* outlining the potential effect on insurance market transparency were the New Hampshire law to be preempted.....Because New Hampshire's data submission requirements are part of our system of insurance regulation, an area of law not addressed in the *Gobeille* decision, there is a greater likelihood that our efforts will be able to continue. The New Hampshire legislature has already passed a bill aimed at clarifying our data submission requirements in view of the decision. (New Hampshire DHHS)
- x. Despite these concerns regarding the recent Supreme Court ruling regarding ERISA-covered entities, both the Pittsburgh and Pacific Business Groups on Health note that many of their partners are covered by ERISA and yet see properly functional APCDs as being critical to achieving greater quality and value (see above).

## **G. Data Privacy/Security & Cybersecurity Issues**

- i. Regarding sustainability, there is some public debate over the practice of the state APCDs selling data to third parties. Concerns for adequate protection of PHI and proprietary APCD data have been raised, particularly concerning data requested/purchased by third parties and related to whether the third party meets HIPAA requirements for data stewardship. (Anthem, Inc.)
- ii. America's Health Insurance Plans strongly recommended that consideration be given to developing standards regarding how data may be used and who may have access to it. They suggested that if insurers are required to report raw claims data to the state, there should be protections in place to guard against the release of proprietary financial information. In addition, standards should be considered for how states review data requests, with consideration given to placing limits on the use and secondary release of such data. For example, some data release could undermine competition. (America's Health Insurance Plans)
- iii. In this environment of cyber security threats, the development of standards for how data, especially protected health information, should be kept secure is of the utmost importance. (America's Health Insurance Plans)
- iv. There is nothing in OPM's statute that prevents Federal Employee Health Benefit (FEHB) health plans from releasing data to state APCDs. At this time, a few FEHB health plans have confirmed that they have chosen to submit data to their state APCDs, and APCDs and other entities have acknowledged that FEHB plans have submitted FEHB enrollee data along with their other commercial claims. OPM endeavors to develop a consistent program-wide policy encouraging

contracted plans to supply data to state APCDs, especially where there is a state mandate in place. To do so, OPM is in the process of updating its standard contract language and adjusting requirements for plan brochure language. (Office of Personnel Management)

- v. While OPM encouraged health plan collaboration with state APCDs, it also recognized the vital importance of privacy and security. OPM believes that health plans must abide by all existing laws and regulations, and should emulate best practices related to information privacy and security. Furthermore, OPM requires that carriers take all necessary steps to minimize risk and ensure that data shared with any entity, including state APCDs, is secure during transmission as well as at rest on all systems. (Office of Personnel Management)

## **H. Standards: Data & Electronic Exchange**

- i. Payers are asked or required to provide APCD data in a variety of formats. This is burdensome. While many states have very similar requirements for data submission, Virginia supported a standard set of information in the same format across states, cautioning against assuming that payers have unlimited resources to meet varying requirements across states. (Virginia Health Information)
- ii. AHIP felt that standards should be set regarding what data are collected. AHIP noted previous efforts toward standardization that might be used as a starting point. These include the Core Set of APCD Data Elements developed by the APCD Council with multiple stakeholders. There are also the X12 standard for medical claims developed by American National Standards Institute and pharmacy data standards developed by the National Council for Prescription Drug Programs. (America's Health Insurance Plans)
- iii. There have been multiple APCD standards introduced by multiple groups (X12, APCD Council, etc.) and adopted over the last six plus years in an effort to standardize the APCD data elements. Previous efforts toward standardization have yielded a variety of standards which have not resolved the issues with APCD data implementation. Some of these efforts are:
  - Core Set of APCD Data Elements developed by APCD Council with input from multiple stakeholders
  - ASC X12 Post Adjudicated Claims Data Reporting (PACDR) for medical claims reporting.
  - Pharmacy data standards developed National Council for Prescription Drug Programs. (Anthem, Inc.)
- iv. It is the uniqueness of each state's APCD – and the lack of standardization from state to state – that diminishes each state's ability to better understand cost and quality and the state factors that impact both. For example, the absence of standardization in the content and format of data elements, results in policy leaders and researchers being unable to compare and analyze data across state borders and within regions that cross state borders. Inconsistencies in standards relating to data quality and data completeness doom any hopes for accurate assessment and management of population health across state and regional borders. (America's Health Insurance Plans)

- v. Anthem endorsed the need for a single standard that is embraced by all state APCD and claims-database reporting entities. Future opportunities to standardize APCD data reporting need to include:
- Standardizing the underlying technical infrastructure to enable APCD data collection
  - Considering the adoption of a federated data model for APCD states/entities
  - Standardizing the process by which data is collected or accessible
  - Agreement among state APCDs on the data elements which are collected (core data elements)
  - A standard process by which data is processed by the APCD entity methodology used to determine data integrity (data quality & data thresholds)
  - Agreement on a common frequency of the data collection/access efforts
  - Transparency and standardization of the methods and process for aggregating APCD data
  - Standard measures, methods and algorithms for reporting APCD data quality and cost measures including the methods used for defining episode groupers, etc.
  - Standardizing the APCD data security and privacy practices
  - Establishing a uniform data integrity policy that ensures the protection of the data elements that should NOT be released to third parties (group level data, patient identifiers unless masked)
  - Standardizing the format for reporting Payer claims data to the state for Commercial and Medicaid encounter claims data (i.e. ASC X12 PACDR, HL7 resource).
  - Defining new reporting requirements to support value-based payments (payments not tied to encounters or episodes of care) (Anthem, Inc.)
- vi. Anthem also noted that one of the biggest benefits to the adoption of a common Claim-based database and APCD reporting standard for the payer and the state APCD is the economy of reporting claims data the same way to every APCD or Claims-based database across geographies. They added that a uniform model would allow states to regionalize and share the cost for the implementation and maintenance of their claims-based APCD databases, which could ultimately drive down the cost of the claims-based APCDs. They also felt that a more regional based APCD solution greatly benefits researchers who often want to see data stratified across a larger geographical area. To accomplish this economy of scale, state APCDs would need to:
- Agree upon a set of core data elements including data definitions and the format for data reported for each data element.
  - Agree upon the format including headers and trailers for the data extract.
  - Agree upon the pre-processing requirements, data thresholds and data quality checks
  - Agree upon which data elements are required vs. optional
  - Agree upon the inclusion/exclusion criteria for reporting APCD data (Anthem, Inc.)
- vii. Anthem further noted that the lack of standards or a common infrastructure has resulted in very large databases that do not communicate with one another, require substantial resources and cost to maintain. While there may be pockets of value identified by the various states/entities that run these APCDs, their value has not been quantified or measured against their original stated objectives. (Anthem, Inc.)
- viii. Anthem, Inc. has spent significant time, resources, and budget satisfying the data reporting requests of APCD entities. The commitment varies depending on the entity as state APCDs vary in their rules

and practices related to collecting and making data available to the data suppliers. Some states, like Virginia- where APCD participation is voluntary – have made the APCD data available to all data submitters through a tool provided by their vendors. Data submitters pay a fee to participate in the Virginia Health Information APCD and receive the public APCD data as a benefit. (VHI masks the Protected Health Information (PHI) data as well as other defined proprietary data elements.) Other states, like Colorado, charge data submitters to receive data from the APCD and the data request must align with specific “acceptable uses.” In our experience, the costs of supplying data to an APCD typically outweigh any benefits derived from receipt of APCD outputs. (Anthem, Inc.)

- ix. Carriers submitting data in more than one state incur considerable costs for ensuring compliance with each state’s specific requirements. For example, one large insurer that submits to multiple state APCDs reported that for most new implementations, the software, staff, and testing costs to comply can be upwards of \$500,000 per state. When changes are made to Data Submission Guides, the costs of making system modifications can run in the range of \$150,000. These increase the cost of doing business in that state, costs which apply upward pressure on premiums that are paid by individuals, employers, and the states themselves. (America’s Health Insurance Plans)
- x. The timeframes applied to the implementation of the APCDs and subsequent changes to submission guides are compressed; the lack of standardization makes it very difficult for data submitters to comply with data submission requirements. (Anthem, Inc.)
- xi. Claims and Eligibility Data must be modified to meet the processing requirements for each Claims-based/APCD reporting entity. These processing requirements vary by state or Claims-based data reporting entity. There is a lack of standards for APCD data use and claims-based database governance of data requests and data dissemination. Data use challenges include:
  - Many APCD entities do not consult with data submitters when evaluating APCD data use.
  - Many APCD entities lack transparency with respect to their data subscribers and data uses, despite the fact that these databases are intended to promote transparency. (Anthem, Inc.)
- xii. Some APCD entities have developed reports, analysis and measures with proprietary methodologies and algorithms, which results in a lack of transparency in the APCD analysis. This lack of transparency with the reporting methods of APCD data reports was said to impact the ability of researchers, payers, population health, providers and others to willingly collaborate. (Anthem, Inc.)
- xiii. Core data element standards would ensure that the states collect data that is meaningful and available. For example, these data elements should focus on information available from claims for comprehensive, major medical coverage through commercial health plans and government programs. Very importantly, standards for core elements should not require carriers to submit data that they do not otherwise collect, such as race and ethnicity of members, social security numbers, etc. (America’s Health Insurance Plans)
- xiv. Consideration should be given to establishing greater consistency among the APCDs regarding frequency – how often data must be reported and updated. [America’s Health Insurance Plans] also urge standards regarding how often changes to Data Submission Guides will be made. (America’s Health Insurance Plans)ASC X12 provided four suggestions for consideration in the form of written testimony:



- Review current formats in use and future opportunities to standardize reporting formats across states (X12, NCPDP, others).
- Identify benefits, efficiencies and barriers, to the adoption of a common Claims-based Databases/APCD reporting standard.
- Identify emerging reporting needs to support healthcare transformation and payment reform (e.g., capturing non-claims transactions, data linkage, etc.).
- Outline a roadmap for achieving standardization and how NCVHS may engage in a supportive role.
- Use the Designated Standards Maintenance Organization (DSMO) process to recommend adoption of standard transactions developed by the SDOs, specifically ASC X12 and NCPDP. (ASC X12)

## **I. Federal Role: Medicaid, Medicare, OPM, DOL, other**

- i. NCVHS was encouraged to recommend a common technical architecture similar to the model used by Centers for Medicare & Medicaid Services to facilitate the development of a multi-state, federal claims database architecture that would serve multiple reporting and analytical purposes. This common framework should ensure that the minimum necessary data be required for meeting the APCD claims database objectives while ensuring the protection and privacy of patients protected health information by organizations that are HIPAA certified entities.
  - Each state/entity would utilize such common architecture to work toward accomplishing the goals of their APCDs. (Anthem, Inc.)
- ii. Some states are attempting to use the health care claims data to provide reports back to employer groups which may result in anti-competitive negotiating behavior between employers and payers or providers. There is a need for unilateral defined parameters around allowed uses of APCD data. (Anthem, Inc.)
- iii. Virginia currently lacks information on other government sponsored programs including approximately 2.6 million Virginians with insurance coverage through Medicare, TRICARE and FEHP. Having complete information from all government health insurance programs will greatly increase the value of APCDs to all stakeholders. (Virginia Health Information)
- iv. The Office of the National Coordinator for Health Information Technology (ONC) mentioned that Multi-payer claims and clinical data aggregation will be necessary as more providers shift to population based payments in Alternative Payment Models. ONC also felt that there needs to be a scalable more deliberate approach to fostering the development of this infrastructure nationwide to support the HHS and HCP-LAN goals for payment reform, and that one to one sharing between payers and providers is not scalable. Federal and state government have policy levers that could facilitate payer and provider participation in qualified data aggregators. (ONC)

## **J. Potential Future Considerations**

- i. There is a need to continue to address the administrative burden that creates barriers to data collection and use. Data should be relatively inexpensive to produce and use, but we have some way to go before that aim is realized. There is also need to comprehensively bring different data sets together, from payers and providers, but also community service and resources. Combining these additional data will enable improving health outcomes of individuals, for populations, and ensure value, both cost and quality. (New Hampshire DHHS)
- ii. The Committee should be mindful of the ways states use these data, and the importance of preserving those systems that are already in place to the benefit of all consumers, when it makes recommendations. (New Hampshire DHHS)
- iii. It was suggested that, given its role as an advisory body to the Secretary, NCVHS's endorsement of a common APCD technical framework, infrastructure and data model for APCD data reporting would go a long way toward addressing many of the challenges posed by the current lack of standardization. NCVHS can also recommend that adoption of a common APCD technical and data framework be a condition of receiving federal funding to establish/maintain state APCDs (i.e. SIM grants). (Anthem, Inc.)
- iv. Anthem's recommendation would be to establish a multi-state, federated claims data base architecture that would serve multiple reporting and analysis purposes which each state/entity would utilize. This model better supports population health reporting across geographic boundaries. (Anthem, Inc.)
- v. The Committee could contribute to security and data stewardship practices regarding access, redisclosure and reuse of APCD data.

## **Conclusion**

This report provides a summary of the testimony provided to NCVHS by multiple stakeholders and does not reflect the views of NCVHS. The NCVHS Population Health Subcommittee will consider if NCVHS should undertake further work in this area as it develops its work plan for 2018 and beyond.

# APPENDIX 1

**National Committee on Vital and Health Statistics (NCVHS)  
Hearing on Claims-based Databases for Policy Development and Evaluation  
----- Overview and Emerging Issues-----**

**Capital Hilton Hotel  
1001 16<sup>th</sup> Street, NW, Federal A Room  
Washington, DC 20036  
202-393-1000  
Friday, June 17, 2016**

## Agenda

*Unless otherwise specified, each testifier will have 5-15 minutes to present key points followed by public comment Committee Q & A at the end of each Session  
Written testimony is requested to supplement oral testimony*

*Written testimony is welcome from any other individual or organization*

8:00 – 8:15 a.m. Welcome and Introductions

8:15 – 8:30 a.m. Opportunities and Challenges related to Claims-based Databases      Walter Suarez, MD, NCVHS Chair  
Denise Love

### **PART 1: POLICY AND REPORTING ISSUES**

8:30 - 9:30 a.m. **Panel 1A—Value, Purpose, Structure, Public Reporting and Policy Consideration**

- State Representatives      Deb Schiel, MA CHIA  
Ana English, CO CIVHC
- Health Care Cost Institute      Eric Barrette
- Blue Cross/Blue Shield Association      Joel Slackman

**Committee Q&A**

9:30 - 10:45 a.m. **Panel 1B—Data Suppliers, Users – Policy Consideration**

- State Representatives Ben Steffen, *MD MHCC*  
Karynlee Harrington, *ME MHDO*
- Health Plan Representatives Bernie Inskeep, *United Healthcare*  
Leanne Gassaway, *America’s Health Insurance Plans*
- Health Care Cost Institute Eric Barrette  
Kristy Thornton, *Pacific Business Group on Health dial in*
- Employer Representatives Jessica Brooks, *Pittsburg Business Group on Health*  
Sheryl Turney, *Anthem, Inc.*
- ACOs Representative

**Committee Q&A**

10:45 - 11:00 a.m. Break

**PART 2: FEDERAL-STATE ISSUES**

11:00 - 12:30 p.m. **Panel 2—Federal Panel**

- Medicaid / State Doris Lotz, *NH DHHS dial-in*
- Medicaid/National Jessica Kahn, *CMS dial-in* Tyler Brannen, *NH Insurance Dept.*
- State: NAIC
- ONC
- State Representatives Patricia MacTaggart  
Deb Schiel, *MA CHIA*  
Michael Lundberg, *VA Health Information*

**Committee Q&A**

12:30 - 1:30 p.m. LUNCH

**Part 3: STANDARDS: BACKGROUND, EMERGING ISSUES AND CHALLENGES**

1:30 - 2:45 p.m. **Panel 3- Overview of Reporting Standards and Previous Standards Efforts**

- APCD Council Josephine Porter
- Health Plan Representatives Sheryl Turney, *Anthem, Inc.*  
Bernie Inskeep, *United Healthcare*

**Committee Q&A**

- 2:45 - 3:00 p.m. Break
- 3:00 - 3:45 p.m. **Next Steps for Claim-based Database and APCDs** NCVHS Chair
- Facilitated discussion with Committee Members and Testifiers
  - Focus on key messages on current state, challenges, opportunities
  - Cover also the role of Claims-based Databases, including APCDs in a reformed health system (ACOs, PCMHs, MIPS, Alternative Payment Models)
  - Possible areas for recommendations
    - To HHS
    - To Industry
- 3:45 - 4:00 p.m. Public Comment
- 4:00 p.m. Adjournment

### QUESTIONS FOR PANELISTS

Overall, we would like testifiers to consider the following factors that NCVHS might use in evaluating Claims-based Databases (including APCD) standards, code sets, identifiers and opportunities for standardization:

#### **PART 1: POLICY AND REPORTING ISSUES**

- Examples of benefits and value of Claims-based Databases, including APCDs in improving health, quality, access, lowering costs
- Benefits to state, public health, employers, payers, hospitals and providers, consumers
- Most significant issues in implementing Claims-based Databases and APCDs, including limited populations included; differences between fee-for-service and capitated; lack of identifiers; limitations of claims-based data; differences across states
- How are Claims-based Databases and APCDs supported; business and sustainability model
- What are the technical challenges to Claims-based Databases and APCD reporting that inhibits their value
- What is the role of Claims-based Databases including APCDs in a reformed health care system: ACOs, PCMHs, MIPS, and Alternative Payment Models

#### **PART 2: FEDERAL-STATE ISSUES**

- Benefits, challenges, role of Claims-based Databases, including APCDs for Medicare; Status and challenges of sharing Medicare data with Claims-based Databases, including APCDs;
- Benefits, challenges, roles, uses of Claims-based Databases, including APCDs for Medicaid Agencies; Status of sharing Medicaid data with Claims-based Databases, including APCDs
- Legislative issues with Claims-based Databases, including APCDs, including lack of consistency

across state laws, requirements, data collection standards, reporting

- ERISA considerations regarding Claims-based Databases and APCDs; opportunities and challenges moving forward
- SAMHSA / 42 CFR Part 2 issues and Claims-based Databases, including APCDs
- OPM and Claims-based Database efforts

### **PART 3: STANDARDS – EMERGING ISSUES AND CHALLENGES**

- Review current formats in use and future opportunities to standardize reporting formats across states (X12, NCPDP, others).
- Identify benefits, efficiencies and barriers, to the adoption of a common Claims-based Databases/APCD reporting standard.
- Identify emerging reporting needs to support healthcare transformation and payment reform (e.g., capturing non-claims transactions, data linkage, etc.).
- Outline a roadmap for achieving standardization and how NCVHS may engage in a supportive role.