



June 5, 2019

To: U.S. Senate Committee on Health, Education, Labor and Pensions,
LowerHealthCareCosts@help.senate.gov
From: APCD Council, on behalf of State APCDs
RE: Public Comment on Lower Health Care Costs Act of 2019

On behalf of state health data organizations that collect and maintain statewide All-Payer Claims Databases (APCDs), the All-Payer Claims Database (APCD) Council submits these comments in response to the Senate HELP Committee discussion draft of the “Lower Health Care Costs Act” released on May 23, 2019.

The APCD Council is a learning collaborative of government, private, non-profit, and academic organizations focused on improving the development and deployment of state APCDs. The APCD Council is convened and coordinated by the Institute for Health Policy and Practice (IHPP) at the University of New Hampshire (UNH) and the National Association of Health Data Organizations (NAHDO)¹. Our work includes over 10 years’ experience with state APCDs, working across states and other stakeholders to seek innovative solutions to technical and reporting challenges faced by these large-scale claims data initiatives.

We appreciate the opportunity to provide comment on this important piece of proposed legislation. State agencies and regional health improvement collaboratives have a long history of using administrative claims data to better understand the costs, utilization, and access to healthcare services; as well as supporting public health information needs. The LHCC Act touches much of this work, and we applaud the Committee for proposing specific advances in mitigating surprise billing, reducing prices of prescription drugs, improving transparency in health care, and improving public health. Our comments focus on the ways that state APCDs can support the issues being addressed by this bill, in hopes that it adds strength to the bill’s rationale for investing in state APCD efforts. In doing so, we ask the Committee to consider the support of APCDs not only in Title 3, but throughout the LHCC Act.

¹ NAHDO is a national non-profit educational association dedicated to improving health care through the collection, analysis, and dissemination of health care data. Since 1986, NAHDO has advocated for the public availability of data, balancing the need for privacy protections with the utility and accessibility of data to serve the public good. Our members are state health data organizations that maintain statewide hospital discharge data reporting systems and APCDs



Title I: Ending Surprise Medical Bills

State APCDs have been named in several pieces of state legislation as resources for producing benchmarks or informing arbitration for the purposes of mitigating the impact of surprise medical bills. We applaud the Committee's similar consideration of the use of data in its bill to lower health care costs.

However, in Section 103 - *Resolution*, while each of the three options refers to using "a database free of conflicts of interest that has sufficient information reflecting rates paid to noncontracting individual health care providers", there does not seem to be a connection to the use of state APCDs. State APCDs are currently using APCD data to support this type of activity. The LHCC Act represents an opportunity to make this connection clear by naming these data resources in the proposed legislation.

Title II: Reducing the Prices of Prescription Drugs

Prescription drug spending is a critical issue that has been and will continue to be supported with information gleaned from state APCDs. Many state APCDs collect paid pharmacy claims data and have used the data in analysis to understand trends in pharmaceutical use and cost at the state and local level.

For example, Minnesota produced the "Pharmaceutical Spending and Use in Minnesota: 2009-2013" report from state APCD data². In 2018, Massachusetts produced a report focused on the drivers of pharmacy spending in fiscal year 2015, which provided information on high volume and high cost drugs in the top 10 therapeutic classes, as well as the associated illnesses they are used to treat³.

As in other sections of the LHCC Act, APCDs could be named specifically as a resource for understanding and mitigating some of these health care cost issues, providing state and sub-state data to drive decision making at the local level, reflective of the unique market challenges in various geographic areas. Defining the connection between claims databases and the rich information that can be derived for the purposes of reducing prices of prescription drugs will not only support the understanding of the drug spending and use (including prescribing patterns), but also highlight the important value, utility and cost of maintaining state APCDs.

² Pharmaceutical Spending and Use in Minnesota: 2009-2013

<https://www.health.state.mn.us/data/apcd/docs/RxIssueBrief1Proof20161102.pdf> accessed May 30, 2019

³ <http://www.chiamass.gov/assets/docs/r/pubs/18/Prescription-Drug-Use-and-Spending-Aug2018-Report.PDF>



Title III: Improving Transparency in Health Care

The APCD Council is very supportive of the effort to increase transparency through the collection of paid administrative claims data; it is at the core of the work of state APCDs and has been for many years. Comments below reflect more detailed considerations for the data collection effort.

The opportunity to fill the ERISA self-insured data gap in state APCDs is promising to states. However, we are concerned about the mechanics of the collection process for ERISA self-insured claims data at the national level. If the data must first be reported at the national level and then re-released to state APCDs, this could create delays in the receipt of the self-insured data by the state APCDs and diminish the utility of the self-insured data for state APCDs.

Any national effort should not be in lieu of state APCDs. The LHCC Act outlines that the national database will “facilitate State-led initiatives to lower health care costs and improve quality.” To be clear, state APCDs are already supporting a myriad of data uses at the state and local level. Given the long history of states using state APCDs, we propose that giving states the ability to collect the data for their populations would better meet this need.

Having data at the national level could support national policy issues. The existing partnership model between the Agency for Healthcare Research and Quality and the states to support the Health Care Utilization Project (H-CUP) database leverages state-based collection of hospital discharge data to answer national questions. The AHRQ HCUP Federal-State-Industry partnership has been a successful, cost-effective model since 1988, and could be considered for this legislation, as well.

State APCDs have deep experience with 1) managing data intake from all the data suppliers and their multiple lines of business, 2) data processing, and 3) aggregation and quality assurance processes for claims data. States that currently have APCDs could apply this experience and streamline the process, maximizing the utility of the data collection at the state and national levels. Therefore, we encourage the Committee to have ERISA plan data submitted to state APCDs (in a standardized format) with states submitting data to a national database. The APCD Council partnered with the National Academy of State Health Policy to contemplate how to leverage the Department of Labor (DOL)’s authority for this type of collection effort.⁴

⁴ Comments on Department of Labor Notice of Proposed Rulemaking Docket # EBSA-2016-0010; RIN 1210-AB63, Submitted by the National Academy for State Health Policy (NASHP), in collaboration with National Association of Health Data Organizations (NAHDO), and the APCD Council, https://nashp.org/wp-content/uploads/2016/10/CA_-Final_-NASHP-Comments-and-Proposal-to-DOL.pdf, accessed June 3, 2019



Specific questions/comments follow:

Section (page) line	Question/Comment
Section 303 (page 73) line 17; “...to be shared with State all-payer claims databases at cost...”	Please clarify what is meant by “at cost” (e.g. CMS uses a tiered pricing schedule for release of Medicare data to State entities)
	Will the national entity be financed to purchase data from state APCDs (some states have fees)?
	May states receive Medicare data from the national entity, in addition to the self-insured data?
	Will the release of self-funded ERISA data from the national entity to the state APCDs be defined by members residence?
Section 303 (page 73) line 18 “...using a standardized format, if such State databases also submit claims data to the database established under this section...”	Please clarify if a State may receive data only IF they submit data to the national entity. Will the intent of the legislation allow states to apply for the use of the data, even in the absence of a state APCD? We strongly encourage the governance to be structured in such a way to maximize the use of the data at the national and state level.
Section 303 (page 74) line 10 Privacy and Security	In some cases, state law is more restrictive than federal law. If state APCD data is submitted to the national entity, how will the privacy laws of the State be maintained?
Section 303 (page 78) line 20 “...2 additional members...”	We strongly recommend that a representative of state APCDs be included in the composition of the Advisory Committee. We also recommend a representative from the data standards community be included in the composition of the Advisory Committee to bridge the communication between the Committee and the national entity on technical aspects of format of data submission.
Section 303 (page 79) line 4	State APCDs should have the opportunity to provide input and review before the standard format is finalized.



Section (page) line	Question/Comment
<p>“...the scope and format of the data to be submitted under subsection d”</p>	<p>A group of states and payers that submit to state APCDs have developed the APCD-CDL™, a common data layout which could inform the development of the final standard format. The APCD-CDL™ is available here: https://www.apcdouncil.org/common-data-layout</p>
<p>Section 303 (page 79) line 23 “... a state may require health insurance issuers and other payers to submit claims data to the database established under this section...”</p>	<p>Does this only pertain to those states without an APCD? It is important that the proposed legislation make clear that any national effort is not in lieu of state data collection efforts.</p>
<p>Section 303 (page 83) line 16 De-identification of Data</p>	<p>If states are submitting data to the national entity, which party is responsible for de-identifying the data? Will the national entity provide a pre-processor that will be used by all data submitters to hash the data?</p>
	<p>Some states expressed that they may need to amend their law to be able to provide identifiable data to the entity.</p>
	<p>Without identifiable data from states, will the national entity be able to integrate state data to meet the needs of the LHCC Act?</p>
<p>Section 303 (page 86) line 1 STATE DATA</p>	<p>Some state APCDs include Medicaid & Medicare data that may or may not be submitted to the national entity (per state law). Is the intent of the law that states will be required to submit all data in their data system to a national effort?</p> <p>Will there be an MOU or DUA with state APCDs? Please clarify the data sharing/access arrangement.</p>
<p>Section 303 (page 85) line 5 “...Is one of the 5 largest administrators or issuers of self-insured group health plans in a State...”</p>	<p>Some states are concerned that this will not really capture much of the self-funded population in their state, if there are many small administrators in the state.</p>



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Section 303 (page 85) line 19 Receiving Other Information	This bill presents an opportunity to address the various interpretations of the legal requirements of Title 42 of the Code of Federal Regulations (CFR) Part 2 and authorize the disclosure of information for uses described in the draft legislation.
Section 303 (page 86) line 6 “...an entity required to submit data under this subsection may not place any restrictions on the use of such data by authorized users...”	While states are not “required” to submit to the national database, is the intent of this language that the only rules that will be retained are those that are established by the Governance Committee, and state laws and terms of use will not apply?
Section 303 (page 86) line 20 “... an entity may request authorization by the entity awarded the contact under subsection (a) for access to the database in accordance with this paragraph...”	The language suggests that authorized users, including states, will not receive a copy of self-insured data in the proposed national data collection model; access through an enclave is not acceptable to states, as it does not permit integration of the data with other state APCD data.
Section 303 (page 90) line 22	While state APCDs and the APCD Council are very supportive of the funding for state APCDs, we would be happy to work with the Committee to develop more sensitive estimates for the continued development and maintenance of state APCDs. We believe that \$100,000,000 over ten years may not adequately support the state APCDs in a way to achieve the cost control efforts described in the bill.
Section 303 (page 91) line 17 Definition of “Proprietary Financial Information”	Please clarify that information about the amounts paid by payers to providers for services rendered will be available in the national database; otherwise, the intent of the database to achieve transparency will not be met. State APCDs have worked with payers to understand the intersection of anti-trust laws and the nature of the information retained in APCDs. That work ensures that transparency efforts are based on accurate data while meeting concerns about the release of proprietary information.



Section (page) line	Question/Comment
Section 304 (page 93)	<p>While we support the effort for payers to maintain current provider directories, we believe a current and uniform provider directory for analytic purposes would meet a need at that state and national level; maintaining the NPPES could be established as a priority under the LHCC Act.</p> <p>A current and accurate provider directory with maps of professionals to organizations would be invaluable to state ACPDs.</p>
Section 306 (page 99) Health Plan Oversight of PBM Services	<p>As this section of the Act evolves, state APCDs may be a resource for monitoring and reporting. Several state APCDs have developed processes to collect drug rebate information, and others are actively exploring collection of this information. However, there may be Federal restrictions that limit that data collection at the individual drug level, which could be addressed through this legislation.</p> <p>States have also become more active in the regulation of pharmacy benefit managers (PBMs), including examination of reimbursement practices. For example, in 2018 Arkansas became the first state to pass a law to require licensure and regulatory oversight of PBMs in 2018. Regulations issued pursuant to the law look to the Arkansas APCD as a potential source for monitoring and reporting.</p>

Title IV: Improving Public Health

In Section 405 (page 139), with regard to Public Health Data Systems Modernization, the APCD Council would like to point out that APCDs are essentially public health data systems. APCD data have been used to describe a number of critical public health issues.

“State APCD systems in Virginia, Utah, and Minnesota have used data from their APCDs to track opioid prescription claims across geographic areas and patient characteristics to understand and address trends in the epidemic. In Colorado, CIVHC analyzed data from its APCD to provide estimates of the population with diagnoses of hypertension and diabetes in Medicaid, Medicare, and commercially insured populations. The report also



showed the change in disease prevalence over time. Virginia also released a summary review of chronic condition prevalence and cost in the state, finding the overall cost for people with at least one of the state’s five most prevalent chronic conditions was four times higher than for those without. Such information could be useful in targeting public health campaigns around certain conditions and geographic areas. APCDs have also been used in New Hampshire to support public health research in the prevalence and use of diabetes self-management education (DSME), breast cancer screening, and tobacco use treatment”.⁵

As public health data systems, APCDs could benefit from investments in standardization and interoperability. While states and data submitters have worked to develop a Common Data Layout, APCD-CDL™, the full implementation and maintenance of the APCD-CDL™ is a significant initiative that will require resources at the state and national level.

In closing, we reiterate our appreciation of the Committee’s attention to a wide range of issues that impact health care costs. State data systems are well poised to support further efforts to contain costs and protect consumers. Thank you in advance for your consideration of the modifications and clarifications outlined in our comments.

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⁵ “The ABCs of APCDs: How States are Using Claims Data to Understand and Improve Care”, November 8, 2018, Jo Porter and Denise Love, California Health Care Foundation, <https://www.chcf.org/wp-content/uploads/2018/11/TheABCsofAPCDs.pdf> accessed on June 3, 2019