APCD Funding

Funding for a state APCD can take a number of forms. In Delaware, the APCD is funded by grants or other independent funding sources.¹² In Utah, Nevada, Vermont, Oregon and Minnesota, the APCDs receive funds from general appropriations, while in Maine the APCD is funded at least partially by the health systems.⁴⁵ Virginia receives a mix of funding from insurers, the Virginia Hospital and Health Care Association, and Virginia Health Information.⁴⁶ Maryland is similarly funded from multiple sources, including payers, hospitals, health occupational boards, and nursing homes.⁴⁷

When possible, the claims data from an APCD should be analyzed in conjunction with data from other sources.

The actual costs per year for the APCD vary depending on the uses. The APCD in Vermont, which is funded by the state, costs approximately \$750,000 per year, including data collection, processing, consolidation, analytics, report generation, and staff time.⁴⁸ The Maryland APCD, which is established for policy decisions and does not have transparency applications for consumers, payers, or noncontract researchers, costs approximately \$1 million dollars a year, including collection fees, analytic costs, policy analysis, and system maintenance.⁴⁹ One of the newer state APCDs, Tennessee, has an annual budget of approximately \$500,000.⁵⁰ A summary of internal cost estimates calculated the initial, first year cost of an APCD to be approximately \$593,750.⁵¹ These expenses do not include the administrative expenses incurred by insurers for submitting their data to the APCD.

The Task Force recommends that the primary uses of the North Carolina APCD be for public health surveillance, policy, and research. If the APCD primarily serves public health purposes, the Task Force believes that it should be primarily funded by a recurring appropriation from the North Carolina General Assembly. Payers and health systems do not have the potential to derive as much value from the database as policy makers and other users and should not be considered as sources for funding. Depending on how the APCD is designed, there is potential for significant Medicaid cost-sharing. The governing board can explore supplemental funding from Medicaid, philanthropy, Health Information Technology for Economic and Clinical Health (HITECH), and data use fees.

Some states charge data users reasonable rates that are based on the expense of producing the file and the amount of data or level of data requested.⁵² A potential model is to charge an hourly rate based on the actual time it takes to consult with investigators and policy makers, and program and transfer the data to a secure site. Another potential model is an average charge for consulting and analysis, which allows users to predict their costs and budget for it. Neither model takes into account the fixed infrastructure costs of the database. The Task Force considers data use fees a potential way to defray the cost of an APCD, but feels that use and access to the database should be prioritized over collection of data use fees.

Recommendation 4: The North Carolina General Assembly should appropriate recurring funding to support the North Carolina APCD. The North Carolina General Assembly and the North Carolina APCD governing board should explore supplemental funding from Medicaid funds, philanthropy, HITECH, and data use fees.

Designing an APCD to Leverage Existing Databases

North Carolina has engaged in large database projects over the past few years, including North Carolina Families Accessing Services through Technology (NC FAST) and Medicaid analytics projects. The support for these databases is indicative of the importance of data and electronic analysis in health care today. The APCD would provide additional critical information to measure and manage health care. When possible, the claims data from an APCD should be analyzed in conjunction with data from other sources.

North Carolina Health Information Exchange

An APCD is a powerful tool for improving population health. To strengthen this tool, many states are exploring combining claims data with clinical data. NC HealthConnex, the state-designated HIE, is currently being implemented. A future goal is to integrate clinical data from NC HealthConnex and claims data from an APCD. Future integration would offer a more comprehensive picture of patient health care, including a complete set of patient diagnoses and costs, improved condition identification, analysis of an individual's care over time, and additional information such as patients' health risk behaviors.⁵³

The goal of a health information exchange is to allow providers access to, and facilitate sharing of, a patient's medical information. The electronic health information exchange moves providers to electronic platforms that can be shared across providers and systems. Sharing patient information improves provider decision-

i A state can receive a 90/10 match for the development of the Medicaid claims pipeline to the APCD. Once "live", the state can receive 75/25 match for the maintenance of the pipeline. If the APCD is on a subscription model, the state can receive a 50/50 match for the fee that the state Medicaid pays. If the APCD is fulfilling a role in support of state's Medicaid Management Information System, then the state can receive a 90/10 match for the Medicaid share of the APCD. Kahn, Jessica. Director, Data and Systems Group, Center for Medicaid and CHIP Services, Center for Medicare and Medicaid Services. Personal (email) communication. Friday, March 17, 2017.

making and diagnoses, while avoiding readmission, medication errors, and duplicate testing. 54

The HIE was created because the North Carolina General Assembly is concerned with "controlling escalating health care costs of the Medicaid program" and believes that the state "needs timely access to certain demographic and clinical information...in order to assess performance, improve health outcomes, pinpoint medical expense trends, identify beneficiary health risks, and evaluate how the state is spending money on Medicaid and other State-funded health services." Therefore, the North Carolina Health Information Exchange Authority was created in 2015 to

The data warehouse and the research networks could be linked with claims data, leading to an even more robust database.

"improve the quality of health care delivery within this State by facilitating and regulating the use of a voluntary, statewide health information exchange network." The health information exchange will "facilitate the creation of a modernized health information exchange (HIE) to better serve North Carolina's health care providers and their patients." The state believes that making demographic and clinical information available to providers will improve care coordination; increase care quality for Medicaid and other state funded health beneficiaries; enable more effective population health management; reduce duplication of medical services; augment syndromic surveillance; allow more accurate measurement of care services and outcomes; increase strategic knowledge about the health of the population; and facilitate health care cost containment." ¹³

The North Carolina General Assembly passed legislation that requires certain entities, as a condition of receiving state funds, to submit twice daily to the HIE network. These entities must submit "demographic and clinical information pertaining to services rendered to Medicaid and other State-funded health care program beneficiaries and paid for with Medicaid or other State-funded health care funds, solely for the purposes set forth in subsection (a) of this section:

- Each hospital, as defined in G.S. 131E-76(3), that has an electronic health record system.
- Each Medicaid provider
- Each provider that receives State funds for the provision of health services"

Leveraging the APCD and the HIE could create a robust, comprehensive view of health care in North Carolina. In order to do so, the data must be identified so that the APCD and HIE can be linked. While it is not yet possible to combine the two data sets, there is future potential for analyses of health risk behaviors, subsequent diagnoses, and expense associated with that care, which would provide a richer tool for population health analytics. As previously mentioned, no states have yet linked an HIE with an APCD, but there are regional data collaboratives that have successfully combined claims and clinical data for powerful regional population health analytics.

North Carolina Human Services Data

Other human services data from North Carolina should be utilized in coordinated ways with claims data. For instance, NC FAST is a tool to streamline the work of the North Carolina Department of Health and Human Services and the North Carolina Department of Social Services. It shows eligibility and determination of benefits for a variety of services, such as Food and Nutrition Services, Medicaid, Work First, and NC Child Care. An APCD linked to NC FAST would allow policy makers at the local and state levels to see the public cost and benefit of both providing services and not providing services. The data from the APCD can be used to analyze how procuring Medicaid benefits influences stable employment or how a day care subsidy influences health care utilization for a child or his/her parents.

Carolina Data Warehouse

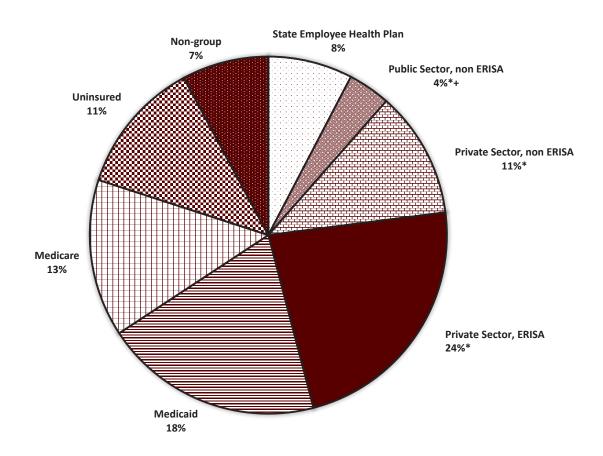
The Carolina Data Warehouse for Health, a joint activity between the University of North Carolina at Chapel Hill (UNC-CH) and UNC Health Care System, is a collection of electronic health record data. It has data on approximately 4.8 million unique patients. The Carolina Data Warehouse for Health includes information on patient demographics, encounter details, diagnoses, procedures, providers, patient vitals, lab tests, medications, orders, notes, charges and payers, surgery, labor and delivery, medical and social history, and patient-reported data. Researchers use this information for clinical operations research and quality improvement projects. They can also use the data warehouse to create registries to support population health.

A Clinical Data Research Network (CDRN) allows for the sharing of clinical data across networks; for instance, UNC-CH is participating in a clinical data research network with the Carolinas Collaborative (UNC-CH, Duke, Wake Forest, and Health Sciences South Carolina) and the Mid-South CDRN (Vanderbilt, UNC-CH, Duke, and Health Sciences South Carolina). The CDRNs are part of the national Patient Centered Outcomes Research Network (PCORnet). The CDRN is a federated data model where the data and the data warehouses stay distinct. Each organization controls the use of their own data, but through the use of a common data model the different organizations can be accessed without having to physically share or move each institution's data from

behind institutional firewalls.56

The data warehouse and the research networks could be linked with claims data, leading to an even more robust database. Because our integrated delivery systems are open—meaning that a patient can choose to receive care inside or outside of the health delivery system—the only way to truly have a comprehensive picture of a patient is through claims data. Claims data is less detailed, but provides a comprehensive, longitudinal view of the patient's care. Currently, the North Carolina CDRNs are testing claims data linkages with BCBSNC and CMS Medicare fee-for-service claims under data use agreements.⁵⁶

Figure 2: Distribution of Insurance Coverage in North Carolina



Source. NCIOM calculations using [Health Insurance Coverage of the Total Population], http://kff.org/other/state-indicator/total-population/?dataView=0¤tTimeframe=0&selectedRows=%7B%22nested%22:%7B%22north-carolina%22:%7B%7D%7D. Accessed March 16, 2017. [Table II.B.1 Number of private-sector enrollees that are enrolled in self-insured plans at establishments that offer health insurance by firm size and State: United States, united States, 2015, https://meps.ahrq.gov/data_stats/summ_tables/insr/state/series_2/2015/tiib1.pdf. Accessed March 16, 2017. [Local Government Employment and Payroll Data: March 2015. Annual Survey of Public Employment & Payroll], https://factfinder.census.gov/faces/tableservices/isf/pages/productview.xhtml?src=bkmk. Accessed March 16, 2017. Welcome to the State Health Plan for Teachers and State Employees. https://shp.nctreasurer.com/AboutSHP/who_we_are/Pages/default.aspx. Accessed March 17, 2017.

Figure 2. Data Notes

This is an estimation based on available 2015 and 2016 data. This does not include Tricare, Champis, or Federal Employee Health Plans. Totals do not add to 100% due to rounding.

- * Values represent the total number of employees with these insurance plans and does not include dependents.
- +Represents the number of full time employees working in local government. City and County government workers do not have their own plan. Some local government employees are covered under the State Employee Health Plan,

CDRNs are functionally distinct from the HIE. The HIE is used when external data about a single patient is needed in the course of that patient's clinical care; for example, to understand care received at an external hospital. CDRNs are designed to query across many patients at once, over long periods of time, in support of population health type question and answering.⁵⁶ An example query is "How many diabetic patients across the

CDRN have not had a foot exam in the last three years, and how do their outcomes compare to those who have regular foot exams?"

Identified Data

Identified data are necessary if the eventual goal of the APCD is to integrate claims and clinical data or link public health databases. Most other state APCDs collect identified data but only release de-identified data. There are various methods for linking including direct, unique identifiers (eg, name, address, insurance or social security number) and indirect identifiers (eg, date of birth, gender, zip code).

APCDs strive to be what their name implies: a database that includes all claims from all the payers within a region.

Federal and State Laws

There are various federal and state laws that protect the privacy, security, and confidentiality of patient health information. The APCD should collect and manage any identified data in accordance with these laws, including the Health Insurance Portability and Accountability Act (HIPAA), 42 CFR Part 2: Confidentiality of Substance Use Disorder Patient Records, and any other applicable laws.

In 1996, the Federal Trade Commission and the Department of Justice issued guidance entitled *Statement of Antitrust Enforcement Policy in Health Care*. Statement 6 of this document, "Statement of Department of Justice and Federal Trade Commission Enforcement Policy on Provider Participation in Exchanges of Price and Cost Information" is pertinent to the discussion of an APCD. This statement establishes a safety zone for the "exchanges of price and cost information among providers that will not be challenged by the Agencies under the antitrust laws, absent extraordinary circumstances." ⁵⁷ In order to meet the safety zone requirements, health care surveys or exchanges of price information must be:

- Managed by a third party.
- Based on data more than three months old.
- Reported by at least five providers, with no provider's data comprising more than 25% on the weighted basis of that statistic, and aggregated so that it would not allow the recipients to identify the prices charged or compensation paid by any particular provider.⁵⁷

Analysis provided by the Center for Improving Value in Health Care concluded that most reports generated by APCD data can be designed to satisfy these three conditions and fall within the safety zone. According to their report, "it is well settled today that the exchange of price or cost information is not unlawful unless it leads to an unlawful agreement by two or more competitors to set or 'fix' their prices." 25 Administrator of the Colorado All Payer Claims Database (APCD

If a report or dataset does not satisfy the safety zone criteria above, it is not necessarily illegal, but it will be evaluated "to determine whether the information exchange may have an anticompetitive effect that outweighs any procompetitive justification for the exchange." This could occur, for example, if the data is reported by small geographic units (city or county) because a single hospital and a single insurer will effectively reveal protected information.

Because of the tremendous potential in leveraging human services, clinical data, and claims data for public health surveillance and research, the Task Force recommends:

Recommendation 5: The North Carolina APCD should be designed in conjunction with other sources of health and human services data as well as existing data systems.

Recommendation 6: The North Carolina APCD should collect and manage identified data in accordance with federal and state law.

Data Included in an APCD

APCDs strive to be what their name implies: a database that includes all claims from all the payers within a region. In order to be the most comprehensive, the North Carolina database should include medical, pharmacy, dental, substance use, and, potentially, "information only" claims (claims not submitted for payment on uninsured patients) from public and private payers, including Medicaid, Medicare, BCBSNC, UnitedHealthCare, the State Employee Health Plan, and others. Having a comprehensive, longitudinal database allows for analysis across the health spectrum of the insured—and potentially uninsured—population in North Carolina. Figure 2 depicts proportions of the state's population covered or not by various payers.

APCD DATA

Exempt Plans

A potential gap in the APCD is the absence of claims data from self-funded plans. In 2016, the United States Supreme Court declared in Gobeille v. Liberty Mutual that state-based APCDs cannot mandate that self-funded plans governed by the federal Employee Retirement Income Security Act (ERISA) statute submit their claims to state databases.⁵⁸ This case has created a significant data gap for all APCDs.

In this case, Liberty Mutual challenged a Vermont statute that mandated that all plans, including self-funded health plans, submit claims data in the required format to the APCD as being preempted by ERISA. ERISA applies to all employee pension, health, and other benefit plans established by private sector employers or by employee organizations who meet certain requirements. The Supreme Court has interpreted the ERISA preemption clause to preempt any state law that either (a) refers explicitly to an ERISA plan or (b) has a substantial financial or administrative impact on the plans.⁵⁸ It should be noted that ERISA does not apply to plans administered by federal, state, or local governments. This means that in North Carolina, the State Employee Health Plan or plans administered for other local governmental entities do not fall under ERISA or its preemption provision.

In the Gobeille case, Vermont argued that their state statute had only an indirect effect on ERISA governed plans and was not unduly burdensome, while Liberty Mutual argued that Congress clearly intended to spare the self-funded employers the potential burden of inconsistent state mandates. The Court concluded that the ERISA preemption "is necessary to prevent states from imposing novel, inconsistent, and burdensome reporting requirements on plans." The court also said that if multiple states had databases with differing timelines or submission requirements, it "could create wasteful administrative costs and threaten to subject plans to wideranging liability."⁵⁸

As a result of the Gobeille v. Liberty Mutual decision, self-funded health plans do not have to submit claims data to state APCDs. Third-party administrators, who typically handle self-funded employee sponsored plans, cannot be compelled to submit the claims. However, the self-funded plans may choose to allow the third-party administrator to continue to submit claims. Health insurance companies, providers, and government health plans must still comply with a state's APCD statute.

The Gobeille v. Liberty Mutual decision concluded by stating that "the Secretary of Labor, not the States, is authorized to administer the reporting requirements of plans governed by ERISA. He may exempt plans from ERISA reporting requirements altogether.....and he may be authorized to require ERISA plans to report data similar to that which Vermont seeks...Either way, the uniform rule design of ERISA makes it clear that these decisions are for federal authorities, not the separate states." The opinion posited that the Secretary of Labor is authorized to require ERISA plans to report additional data. Subsequently, the Department of Labor (DOL) issued proposed revisions to Form 5500, the Annual Return/Report of Employee Benefit Plans and Form 5500-SF, Short Form Annual Return/Report for Small Employee Benefit Plans. The DOL specifically requested public comments on the rules in light of the Gobeille case, but it is unclear at this time how the DOL will move forward.

The Gobeille case is having a significant impact on state APCDs. Approximately 24% of North Carolina residents are funded by plans that cannot be compelled to share data under the Gobeille case. This includes a majority of individuals with employer-sponsored coverage. Nationally, 63% of individuals insured through their employer are on a self-funded plan. In North Carolina, 65.6% of private sector employees who work in firms that offer health insurance are in self-funded plans and covered by ERISA. That means that a significant portion of the North Carolina private insurance market cannot be mandated by the state to submit claims data. See the figure for estimates of market coverage. In order to maximize the APCD's value to all parties, the implementation plan should include efforts to find a suitable common data format for the submission of data from self-funded health plans that satisfies both the APCD's needs and minimizes the impact on employer compliance. This may include working with the APCD Council and the US Departments of Labor and Health and Human Services to develop a single, national standard for this data.

Substance Use Claims

Substance use claims have additional regulations, beyond HIPAA restrictions, and can only be included in an APCD if the organizational home of the APCD meets certain requirements. Substance use claims are governed by 42 CFR Part 2: Confidentiality of Substance Use Disorder Patient Records. The statute applies to any individual or entity that is "federally assisted and hold[s] itself out as providing...alcohol or drug abuse

diagnosis, treatment or referral for treatment." A program is federally assisted if it is "authorized, licensed, certified or registered by the federal government; receives federal funds in any form, even if the funds do not directly pay for the alcohol or drug abuse services; is assisted by the Internal Revenue Service through a grant of tax exempt status or allowance of tax deductions for contributions; is authorized to conduct business by the federal government; or is conducted directly by the federal government." The regulations impose restrictions on the disclosure and use of information that identifies a patient, directly or indirectly, as having a current or past drug or alcohol problem or as a participant in a covered program. 42 CFR Part 2 requires patients to consent in writing to the disclosure of their records for the purposes of health care operations, treatment, or payment.⁶²

The inclusion of substance claims could allow researchers to better understand the prevalence of substance use disorders, the accessibility of treatment, and the effectiveness of community assessment and improvement programs.

In early 2015, the US Substance Abuse and Mental Health Services

Administration suggested proposed changes to 42 CFR Part 2. The goal of the changes "is to facilitate information exchange within new health care models while addressing the legitimate privacy concerns of patients seeking treatment for a substance use disorder." These new rules, finalized in January 2017 and effective in February 2017, are meant to facilitate electronic exchange of information for treatment and health care purposes.⁶³

Substance use claims are especially important in light of the rapid increase in opioid usage. The inclusion of substance claims could allow researchers to better understand the prevalence of substance use disorders, the accessibility of treatment, and the effectiveness of community assessment and improvement programs. For example, claims data and other health information was analyzed to evaluate opioid use in Massachusetts and led to four key findings: first, "prescription drugs fuel this epidemic, but illegally-obtained substances are more closely linked to overdose deaths"; second, "medication assisted treatment reduces the risk of fatal opioid overdose"; third, "women are more likely than men to experience a fatal overdose due to prescription opioid use"; and fourth, "individuals who have recently been released from Massachusetts prisons are 56 times as likely to die from an opioid related overdose [than the general public]."⁶⁴

At the federal level, Medicare recently released a Medicare Part D opioid drug mapping tool that shows comparisons at the state, county, and zip code level of opioid prescription claims.⁶⁵ Researchers are also analyzing claims data for insight into the opioid epidemic; administrative claims data is being analyzed to find characteristics and behavior associated with abuse and to create a model to assist payers in identifying patients with increased risk.⁶⁶ Further studies found that the models can not only identify the individuals at risk for abuse, but can also be generalized and applied to other health plans.⁶⁷

Medicare Claims

In order to obtain claims data from Medicare, North Carolina can execute a state agency data use agreement with Medicare or can apply to become a Qualified Entity (QE).

A state can submit a state agency data use agreement to the Center for Medicare & Medicaid Services (CMS) via a state agency request. This gives the state access to quarterly or annual Medicare data reports to be used for a variety of qualified research purposes. Rather than signing multiple data use agreements for every research purpose that is directed or partially funded by the state, the state agency can reuse the data for additional research by contractually binding all recipients of the protected health information to the terms of the data use agreement. Single data use agreements do not release all Medicare data, but do provide access to enrollment information, the main elements of Part A (hospital insurance) and Part B (medical insurance) claims; Part D (prescription drug event) data set, and assessment data including long-term care Minimum Data Set, Swing Bed Minimum Data Set, home health Outcome and Assessment Information Set, Inpatient Rehabilitation Facility Patient Assessment Instrument, and Medicare Provider and Analysis Review. CMS permits all data to be included in a state APCD.

A QE has access to the same data as a state with a state agency request—including Medicare Part A, Part B, and Part D—which it can receive quarterly or annually. However, the entity is only allowed to use the data to generate performance reports on providers and is required to make these reports available to the public after the providers and suppliers review them. The entity can reuse the claims data for additional research with approval from CMS and through the completion of either a research data use agreement or a state agency data use agreement.⁶⁹

In order to become a Qualified Entity, an organization must:

- Have access to claims data from other sources to combine with the Medicare Data.
- Have strong systems to ensure that the data are secure and protected.

APCD DATA

- Have experience in a variety of tasks related to the calculation and reporting of performance measures, including:
 - o Combining claims data from different payers.
 - o Designing performance reports.
 - o Sharing performance reports with the public.
 - o Working with providers and suppliers regarding request for error correction.
 - o Ensuring the privacy and security of data.⁶⁹

An entity must apply for this designation and, if approved, is certified for three years. The entire process can take approximately 18 months.⁶⁹ An entity is allowed to apply for recertification six months before the conclusion of the three-year term.

The decision to pursue a data use agreement or a qualified entity designation should be decided by the APCD Governing Board.

Information Only Claims on Uninsured Patients

In creating an APCD, it is critical to decide which types of claims should be included. Other state-based APCDs include medical claims, eligibility claims, pharmacy claims, provider claims, and dental claims. Maine is the only APCD to include claims on uninsured patients. The largest health system in Maine issues identification cards to manage care and to track uncompensated care. The health system then submits an information-only claim to a third party administrator, who processes it but does not pay it. This allows the health system and the state to partially document the cost of care to uninsured patients and include those claims in the APCD.⁷⁰

Eleven percent of North Carolinians are uninsured, so it is important to consider opportunities for including these residents in an APCD to understand cost of care for all North Carolinians and to understand opportunities to improve health. The NC FAST database collects demographic information and income information on individuals who request consideration for Medicaid. Because the state is already collecting this information, it has an opportunity to track uncompensated care. This could be achieved by providing individuals who request consideration for Medicaid with a card that indicates their status as a percentage of the federal poverty level. This allows providers and health systems to recognize that the individual is prescreened (through NC FAST) and eligible for charity care or a sliding scale payment system. However, submission of information-only claims requires both a system (like Maine's card with a unique ID) and a willingness on the part of providers to submit claims with no expected payment for services. Implementing a program to track uncompensated care through information-only claims requires the providers, health systems, and an insurer to voluntarily assume this burden, and therefore no penalty should be attached for noncompliance. Information-only claims data are very important for identifying high risk patients when they move into Medicaid and evaluating the costs and benefits of uncompensated care, Medicaid expansion, and the federal program that replaces the Affordable Care Act.

Recommendation 7: The North Carolina APCD should collect all claims data. Proxy data on uninsured patients should be incorporated into the database in the future if feasible.

Data Layout for the APCD

An APCD can be used to benchmark with other states. If North Carolina wants to accurately compare health care costs in this state with those in other states, then the North Carolina APCD must use a common data layout. A common data layout ensures that states with APCDs are collecting similar information. For example, New England, Maine, New Hampshire, and Vermont worked to harmonize their data layout in order to create regional analysis. North Carolina may want to proceed similarly in the southeast.

In addition, an APCD requires payers to submit data in a standardized form for the APCD to store. It is burdensome, time consuming, and expensive for payers to change the file type and submit to a database, and if they are participating in multiple state-level APCDs, the cost and burden increases with each new process. Multiple states, including Washington, Colorado, Utah, Maine, and Virginia, are using APCD Core, a standardized data layout. Additionally, the National Association of Health Data Organizations, national payers, the APCD Council, and others are in the process of creating a common data layout.

Recommendation 8: If feasible, the North Carolina APCD should adopt a standard data model.

j Inskeep, Bernie. Regulatory Financial Operations, APCD Program Director, UnitedHealthCare. Personal communication. Friday, January 26, 2017. k Inskeep, Bernie. Regulatory Financial Operations, APCD Program Director, UnitedHealthCare. Personal communication. Friday, January 26, 2017.