Claims Data to Improve Health in North Carolina: A Report from the NCIOM Task Force on All-Payer Claims Database

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The North Carolina Institute of Medicine (NCIOM) is a nonpolitical source of analysis and advice on important health issues facing the state. The NCIOM convenes stakeholders and other interested people from across the state to study these complex issues and develop workable solutions to improve health care in North Carolina.

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The North Carolina Institute of Medicine’s Task Force on an All-Payer Claims Database was convened in August 2016 with support by The Duke Endowment and AARP NC.

The Task Force was chaired by Blanton Godfrey, PhD, Distinguished University Professor, College of Textiles, North Carolina State University, and Joe Cooper, Chief Information Officer, Information Technology Division, North Carolina Department of Health and Human Services. The Task Force’s work would not have been possible without their leadership.

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Improving the experience of care, reducing the cost of care, and improving population health are critical goals that North Carolina needs to pursue in order to rank higher in national assessments and maintain progress in health care. In 2016, the state ranked 32nd for overall health-down one ranking from 2015. One tool to assist in improving health in North Carolina is an All-Payer Claims Database (APCD). An APCD is an extensive database that collects claims data from public (eg, Medicare, Medicaid, state health plans) and private health insurance payers.

APCDs can be used to inform public health and public policy priorities, evaluate the outcomes of public health programs and policies, determine the actual cost of health care in a state, provide consumer transparency, analyze geographic variation in health, and more. Currently, 22 states are developing or have developed an APCD and are using the data to better understand health care utilization, geographic disparities in care, health care cost, and other critical information.

Claims data have many potential uses because they provide broad information about individuals’ interactions with the health system. A claim is “a request for payment that you or your health care provider submits to your health insurer when you get items or services you think are covered” [by your health insurance policy]. Every time an individual has contact with the health care system, claims data are generated; they can show when an insured individual went to a doctor, had an appointment with a specialist, and filled a prescription. Having access to this comprehensive data increases opportunities to improve quality, control cost, and understand variation in care, all of which are important interests for state government, employers, insurers, providers, and the people of North Carolina.

Task Force Background
With funding from The Duke Endowment, in August 2016 the North Carolina Institute of Medicine (NCIOM) convened the NCIOM All-Payer Claims Database Task Force to study the costs and benefits of creating an APCD in North Carolina. The Task Force met five times between August 2016 and January 2017. The Task Force was chaired by Blanton Godfrey, PhD, Distinguished University Professor, College of Textiles, North Carolina State University, and Joe Cooper, Chief Information Officer, Information Technology Division, North Carolina Department of Health and Human Services. In addition to the co-chairs, the task force had 37 members who represented various payers, health systems, researchers and academics, patients, technology experts, and legislators. A steering committee of six experts guided the Task Force. This report is based on the findings and recommendations of this Task Force over five meetings, each approximately five hours long, from August 2016 to January 2017.

The Task Force had broad, but not unanimous, support for its recommendations from its members. The primary recommendation to establish an APCD was supported by 36 members and opposed by two members with one member abstaining. All members voted. Voting on the remainder of the recommendations generally followed suit.

This report discusses the findings of the NCIOM All-Payer Claims Database Task Force. The charge of the APCD task force was to study the use case of an APCD for North Carolina, examine alternatives to a state-based APCD, and evaluate options for implementing an APCD in North Carolina, including an assessment of legislative interest, governance, and finance. The task force also examined the 22 states with an active APCD or an APCD under development to inform the discussion and identify best practices for implementation. This task force report includes actionable recommendations to move forward towards the creation of an APCD.

Development of a North Carolina All-Payer Claims Database
Claims data can answer many questions about health care for policy makers, employers, health systems, researchers, and consumers, including the types of health care people are using and how much that health care costs in a state. Having this information from all payers across the state would also reveal geographic differences in utilization and cost.

Currently, there is no readily available way to evaluate the total utilization and cost of health care provided in the state. Measuring the cost of health care allows for better management of the costs of health care. Claims data can also show the impact of legislation, allow benchmarking of private and public payers, show geographic disparities across the state for health conditions, determine the cost of those conditions, and more. The task force found that an APCD has compelling opportunities in public health surveillance, planning, evaluation and research but that the design of the APCD should be flexible enough to accommodate for future use cases.

**Recommendation 1:** The North Carolina General Assembly should establish an All-Payer Claims Database (APCD). The goal of the database should be to improve the health of North Carolinians. Primary use cases include population health surveillance, research, and public policy analysis. However, the legislation, regulation, and design of the database should allow for flexibility for other uses as appropriate.

The authority for an APCD is generally created through legislation, and the details of implementation are usually determined by a governing board. An APCD requires a governing board to create regulations, to determine data submission and release, and to handle the infrastructure and maintenance of the database. **Recommendation 2:** The North Carolina General Assembly should create an APCD governing or advisory board that includes...
health care stakeholders. The types of stakeholders to consider include providers, consumers, employers, national and regional payers, public health professionals, researchers, representatives from NC FAST and the HIE, county social service workers, and others. The governing board should be responsible for making recommendations to the General Assembly regarding an organizational home, regulations surrounding submission and release and infrastructure and maintenance, identification of supplemental funding, and other issues as they arise.

Most states with an APCD legislatively mandate participation. A mandatory APCD allows for a uniform and comprehensive database. In order to create the most useful database, it is imperative that the database is mandated to ensure that all payers with a modest market share in North Carolina participate, submit data on similar timelines, and face penalties for noncompliance. Recommendation 3: Where legally permissible, the North Carolina General Assembly should require payers who cover 1,000 or more individuals in North Carolina to contribute claims data to the APCD.

The task force recommends that the primary uses of the North Carolina APCD be for public health surveillance 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 derive as much value from the database as other users and should not be considered as initial sources for funding. Depending on how the APCD is designed, there is potential for Medicaid funding. The governing board can explore supplemental funding from Medicaid, philanthropy, Health Information Technology for Economic and Clinical Health (HITECH), and data use fees. Recommendation 4: 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.

North Carolina has engaged in large database projects over the past few years, specifically 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. 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.

Identified data are necessary if the eventual goal of the APCD is to integrate claims and clinical data or link a public health database. Most other state APCDs collect identified data but only release de-identified data. There are various methods for linking data, including direct, unique identifiers (e.g., name, address, insurance or social security number) and indirect identifiers (e.g., date of birth, gender, zip code). Any information in the APCD should be collected and managed in accordance with federal and state law. Recommendation 6: The North Carolina APCD should collect and manage identified data in accordance with federal and state law.

All-Payer Claims Databases 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 from public and private payers, including Medicaid, Medicare, Blue Cross Blue Shield of North Carolina, 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. 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.

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

a 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 a 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, Centers for Medicare & Medicaid Services. Personal (email) communication. Friday, March 17, 2017.


Since 2007, when the Triple Aim was first introduced by the Institute for Healthcare Improvement (IHI), policy makers in North Carolina and around the United States have been working on health initiatives that emphasize the Triple Aim: improving experience of care, reducing cost of care, and improving population health. These are critical goals for North Carolina. Despite these efforts, in 2016 the state ranked 32nd in overall health—down one ranking from 2015.1 This report examines the All-Payer Claims Database (APCD), a tool that can assist North Carolina in meeting the initiatives of the Triple Aim.

An APCD is an extensive database that collects claims data from public (eg, Medicare, Medicaid, state health plans) and private health insurance payers.2 Claims data have many potential uses because they provide broad information about individuals’ interactions with the health system. A claim is “a request for payment that you or your health care provider submits to your health insurer when you get items or services you think are covered [by your health insurance policy].”3 Every time an individual has contact with the health care system, claims data are generated; they can show when an insured individual went to a doctor, had an appointment with a specialist, and filled a prescription. Claims data include information on diagnoses, procedures that are performed, and payment for health care services.

State APCDs collect and compile claims data from health care plans within their state, often with goal of providing comprehensive state-level data on health care utilization and spending. Data from APCDs can be used to inform public health and public policy priorities; evaluate the outcomes of public health programs and policies; determine the actual cost of health care in a state; provide consumer transparency; and analyze geographic variation in health, in addition to accomplishing other tasks.4-8 Currently, 22 states are developing or have developed an APCD and are using the data to better understand health care.9 Having a state-level APCD increases opportunities to improve quality, understand cost increases, and understand variation in care, all of which are important interests for state government, employers, insurers, providers, and the people of North Carolina.

Task Force Background

This Task Force builds upon work done by the North Carolina State University Institute for Emerging Issues (IEI) in June 2014 and December 2014 to explore the utility of an APCD for North Carolina. Those meetings included expert guests who spoke about the functionality, governance, and financing of APCDs in other states. Participants included payers Blue Cross and Blue Shield of North Carolina (BCBSNC), UnitedHealthcare, and accountable care organizations; providers included North Carolina Medical Society, North Carolina Hospital Association, and public and private health systems. Task Force leadership came from the North Carolina Department of Health and Human Services (DHHS), patient advocacy organizations, academics, Area Health Education Centers, and researchers. IEI convened an informal steering committee to discuss the possibility of an APCD in North Carolina, taking into account Medicaid reform, legislative interest, and the state political climate. This steering committee included representation from the North Carolina Department of Health and Human Services, Community Care of North Carolina, NCIOM, IEI, North Carolina Healthcare Information & Communications Alliance, Cornerstone Health Care, Ambrose Strategy, and the North Carolina Medical Society. After the conclusion of the 2015 legislative session, the steering committee agreed that the NCIOM should work with DHHS and seek funding to support a more extensive consideration of an APCD in North Carolina. After obtaining funding support from The Duke Endowment and AARP NC in 2016, the NCIOM convened the Task Force in August 2016.

This report discusses the findings of the NCIOM All-Payer Claims Database Task Force. The charge of the APCD task force was to study potential use cases of an APCD for North Carolina, examine alternatives to a state-based APCD, and evaluate options for implementing an APCD in North Carolina, including an assessment of legislative interest, governance, and finance. The Task Force also examined the 22 states with an active APCD or an APCD under development to inform the discussion and identify best practices for implementation. This Task Force report includes actionable recommendations to move towards the creation of an APCD.

Data from APCDs can be used to inform public health and public policy priorities; evaluate the outcomes of public health programs and policies; determine the actual cost of health care in a state; provide consumer transparency; and analyze geographic variation in health, in addition to accomplishing other tasks.
The Task Force had broad, but not unanimous, support for its recommendations from its members. The primary recommendation to establish an APCD was supported by 36 members and opposed by two members with one member abstaining. All members voted. Voting on the remainder of the recommendations generally followed suit.

**The Value of an All Payer Claims Database**

Claims data can answer many questions about health care for policymakers, employers, health systems, researchers, and consumers, including the types of health care people are using and how much that health care costs in a state. Having this information from all payers across the state can also reveal geographic differences in utilization and cost. Currently, there is no readily available way to evaluate the total utilization and cost of health care provided in North Carolina. Measuring the cost of health care allows for better management of the costs of health care. Claims data can also show the impact of policy, allow benchmarking of private and public payers, show geographic disparities across the state for health conditions, determine the cost of those conditions, and more. The potential uses of an APCD and how APCDs are used in other states are explained below.

**The Value of an APCD for Policymakers**

North Carolina policymakers are concerned with the rising and unsustainable cost of health care as well as the uneven quality and delivery of health care across the state. An APCD would provide data that could be used to better understand and, potentially, manage health care costs. For example, some states are using APCDs to benchmark their Medicaid expenses against private payers within their states. Other state APCDs, like Massachusetts, analyze their claims data and release annual reports on the state health care system. Elements of the report include an assessment of total statewide health care spending and how it changed from the year before in terms of per member per month spending; Medicare spending; total pharmacy spending; provider quality within the state (compared nationally); enrollment coverage; number of high deductible plans; and cost sharing.\(^4\) This annual report card helps the state measure and analyze its performance year by year.

Policymakers are also using APCDs to analyze the impact of health care legislation and determine whether it meets its intended goals. For example, the Maryland APCD issued a report on the impact of legislation intended to decrease the financial burden on patients obtaining care from an out-of-network provider in a hospital. This legislation, titled Assignment of Benefits and Reimbursement of Nonpreferred Providers, was designed to change how nonparticipating, hospital-based, or on-call physicians are reimbursed by insurance plans. The law aimed to reduce the burden on patients by discouraging balance billing, but without reducing the payment to the out-of-network provider. Using the state’s APCD, analysts concluded that the law achieved its intended goal by reducing patient cost burden in these cases.\(^10\)

Some states have identified specific goals or questions to be addressed by their APCDs. Tennessee, for example, has identified the following goals:

- Assess the accessibility, adequacy, and affordability of patient health care and coverage
- Identify health and health care needs and inform health care policy
- Determine the capacity and distribution of existing health care resources
- Evaluate the effectiveness of intervention programs on improving patient outcomes
- Review costs among various treatment settings, providers, and approaches
- Provide publicly available information on health care providers’ quality of care.\(^11\)

In Delaware, the proposed legislation for their APCD asked the following questions:

- How much does Delaware spend on health care?
- How much does a service cost at a specific facility?
- How have health care prices changed over time?
- Are Delaware’s efforts to establish value-based alternatives to the traditional fee-for-service health care system effective?\(^12\)
These goals direct the analyses of APCD data to answer specific policy questions for the state and provide clarity to stakeholders and researchers. Detailing the goals or questions that an APCD should address can ensure its effectiveness.

Similarly, in the statute for the creation of the Health Information Exchange (HIE), the North Carolina General Assembly laid out health care policy concerns it wanted the HIE to address, instructing it to “assess performance, pinpoint medical expenses, identify beneficiary health risks and evaluate how the state is spending money on Medicaid and other State-funded health services.” The HIE has recently started collecting clinical data, and the statute for the HIE currently requires only submission of Medicaid and State Employee Health Plan data.13

Regional APCD collaboratives have linked clinical and claims data, but a state-based APCD has not yet linked to an HIE. An APCD would provide critical data to more completely answer the directives listed in North Carolina’s HIE statute, especially if linked to the HIE in the future. Unlike the HIE, an APCD would include data on a broad population of consumers (all payers), would not require participation in an electronic health record or participation in Medicaid (all providers), and would include a greater array of services (eg, pharmacy filling, durable medical equipment, and oral health services). Furthermore, a large number of individuals in North Carolina come on and off Medicaid each year; in 2016 approximately 710,000 people became Medicaid beneficiaries while almost 626,000 beneficiaries dropped Medicaid coverage.6 This ‘churn’ means that the availability of claims data from all payers would greatly improve our ability to understand the care of populations as they change insurance as well as the total care and cost of care for the population of the state.

The goals of the North Carolina HIE include, “enabling more effective population health management, reducing duplication of medical services, allowing more accurate measurement of care services and outcomes, increasing strategic knowledge about the health of the population and facilitating health care cost containment.”13 The information obtained from an APCD further supports these goals, because claims data allow for analysis of population health and health utilization from a different angle. Therefore, a state APCD would complement the HIE and could advance the investment the North Carolina General Assembly made in the creation of the HIE.

**How Policymakers in Other States are Using APCD Data**

Policymakers in states with APCDs are using the data to inform decision making. APCDs have been used in market regulation to analyze the effects of mergers by health care facilities. For example, Massachusetts is concerned about the effect of rising health care costs on its ability to offer expanded insurance coverage. As a result, the state set a goal to constrain costs. Their APCD is used to monitor provider and insurer spending. The Massachusetts claims data were critical in assessing the impact of a health system acquiring a hospital, and an analysis that ultimately led to the state’s decision to bar the acquisition because they believed it would lead to higher spending and costs.14

APCDs can also be used to analyze the prevalence of various health conditions. In New Hampshire, claims data were used to analyze the prevalence of depression among the Medicaid population, the variation in services for beneficiaries with and without depression, the type of mental health treatment beneficiaries receive (if any), and the relationship between depression and chronic conditions. By analyzing the claims data using two methods—diagnosis of depression and use of an antidepressant—the report found that depression was more prevalent among women and that most Medicaid members with evidence of depression received treatment. The report also found that those with evidence of depression had “substantially higher costs than those without depression and that those with depression and other comorbid medical or mental health conditions had a two-fold increase in payments.” Patients with evidence of depression had, on average, a payment 3.8 times higher than those with no evidence; emergency room usage was 2.5 times higher and hospitalization rates were 4.7 times higher.15 Similarly, Utah published a report on antidepressant use in the state in order to analyze how antidepressants compared to other medications in terms of use and cost, and how usage broke down among age, sex, location, and health status. The report found that 68% of antidepressant prescriptions were for females (more than double the rate for males) and that most prescriptions were for people aged 55-64 years. Antidepressant use was also analyzed by geographic location; findings showed that in one area of the state, 21% of females were prescribed antidepressants in one year, compared to 7.5% of females in a different area.16

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In Oregon, researchers are using state APCD data to review prescription drug costs and trends in order to identify recent utilization for both brand and generic drugs, identify the drugs that have the highest costs for payers, and identify the corresponding medical condition associated with the drugs. This data, requested by a legislative committee, is informing legislation that will be introduced during the 2017 legislative session. Additionally, Oregon is using their APCD to assess the Medicaid reform model and address racial and ethnic health care disparities. Researchers are also reviewing the impact of coordinated care organizations in reducing racial disparities and factors associated with health care performance differences. This analysis will be complemented by a broader assessment of Medicaid in the state and how it performs in comparison to private payers.17

In Minnesota, counties use claims data analyses released by the state APCD for their Community Health Assessments. Their APCD produced a report entitled *Chronic Conditions Minnesota: New Estimates of Prevalence, Cost and Geographic Variation for Insured Minnesotans, 2012*. This report found that 35.4% of residents had at least one chronic condition, more than half of those had multiple chronic conditions, and that the cost per person for those with one or more chronic conditions was eight times higher than those with no chronic condition. The report also included maps showing the variation and prevalence in spending for chronic diseases by county.18 Information from a state APCD can be very useful for counties in their community health assessments because it can provide community-level data, which allows for benchmarking both regionally and statewide.

APCDs can be helpful in analyzing a state’s health care workforce. In Oregon, a report was created to assist policy makers in determining the utility of health care workforce incentives. Using APCD data, the analysts were able to create a projection of future provider needs by looking at utilization of medical services (in the form of visits) by age group, race, gender, insurance type, and county. They combined these projections with US Census Bureau and American Community Survey data in order to project future utilization needs and to demonstrate the need for provider retention across the state. This report found that the incentive programs enacted by legislation in 2015 were successful at retaining and attracting providers to rural and underserved areas, and identified which specific programs were effective in recruitment, which programs were effective in retention, and which programs were successful in both recruitment and retention.17 APCDs may also be helpful in determining state-based workforce needs. For example, claims related to specific diagnoses or procedures may suggest the need for certain types of providers or facilities in a state or region.

Claims data are also being used to assist with reversing the opioid overdose epidemic. The discussion about this epidemic is currently driven by fatalities because those are the data available to the state. In North Carolina, much of the work around opioid overdose and prevention is being driven by emergency department visits and emergency medical services data, since they are more timely and readily available than fatality data.19 Adding prescription filling behavior, lab tests and procedures, and care or drug-seeking behavior can allow for a more comprehensive view of the problem. For example, states can look at typical opioid filling patterns, identify how many providers in a system are outliers, see how patients with chronic pain are using specialists such as behavioral health and pain specialists, and determine how often providers are obtaining urine toxicology results to inform prescribing. In Colorado, claims data are used to evaluate trends in opioid prescription fills. The goal of the study is to “define the incidence and dose of opioid prescriptions at 30 days, 90 days, and 180 days following hospital discharge after major surgery.” While the study is ongoing, the present data can be used to show providers and health systems how they perform on the prescribing spectrum and inform them about best practices.20 Currently in North Carolina, using the very powerful controlled substances reporting system, we can study and report on prescription filling behavior in isolation. Also, Community Care North Carolina (CCNC) utilizes Medicaid claims data to identify individuals who may be at risk of opioid overuse and target them for care management services. The opioid risk “flag” looks for Medicaid patients with greater than 12 narcotic prescription fills and greater than 10 ED visits in the last 12 months and no cancer diagnosis in the recent claims history. These individuals are reported to the local CCNC Network to prioritize the work with them at the local level where it can be combined with local knowledge and resources to best serve the individual. An APCD would allow similar risk analysis for people without Medicaid patients.6

**The Value of an APCD for Improving Public Health and Research**

The Task Force found that an APCD has compelling opportunities in public health surveillance, planning, evaluation, and research. Currently, North Carolina lacks a comprehensive database for analysis of issues such as access to care, geographic variation of care, utilization of services, and disease reporting. An APCD

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C Cline, Steve. Vice President for Strategic Partnerships, Community Care of North Carolina. Personal (email) communication. Thursday, March 16, 2017.
could help fill this existing data gap, allowing for a wider, deeper view of the population. A North Carolina APCD could be used for analysis and reporting of utilization patterns, including access to care, geographic distribution, and overutilization. For instance, looking at the cholesterol screenings in a geographic area can reveal how it impacts heart disease years later in that area. An APCD could help North Carolina researchers and practitioners develop and evaluate targeted public initiatives and interventions. For example, an APCD could provide a better understanding of antibiotic filling practices, health care associated infection rates, and antimicrobial resistance patterns. It could also assess the surveillance gap in occupational-related injuries and illnesses, by allowing for surveillance of work-related health care encounters that may not require hospitalization or review of emergency department utilization. This could allow the state to target public health interventions to areas that need them most and could allow for better evaluation of the interventions that are implemented. In addition, an APCD allows other partners to analyze health care and utilization. For example, as part of the Fostering Health North Carolina project, in specific circumstances Medicaid claims data are shared with local Departments of Social Services to understand the children in their care and what their health needs may be. A similar program in Oregon uses the APCD to examine factors that affect school performance and whether student outcomes correlate to insurance coverage. In Maine, claims data was requested by the Raising Readers program to estimate program eligibility.

This program provides books through well-child visits, and the analysis uses information from vital statistics and the ages and rates of children who receive well-child visits to estimate eligibility and promote early childhood literacy. An APCD can be used by traditional and nontraditional stakeholders to allow for a wider, deeper view of population health while also providing better data to inform health policy.

**How States are Using APCDs to Improve Public Health**

Other states have successfully used their APCDs for public health purposes. In Colorado, researchers used APCD data to assess Hepatitis C prevalence and treatment. They found that only 11% of those with Hepatitis C were receiving any treatment, and of those 11% only 7% were getting the newest and most effective treatment, with 4% receiving older and less effective treatment. Minnesota is using their APCD to estimate the prevalence, cost, and geographic variation of chronic conditions in the state. In Oregon, the APCD is used for public health surveillance of chronic diseases and to describe the burden of those diseases. An APCD cannot track prescribing behavior (a claim is not generated when a prescription is written) but can be used to evaluate treatment by analyzing prescription-filling behavior. It would be possible to evaluate the filling of prescribed medicines in the treatment of these chronic conditions. Such evaluation could lead to public health campaigns or provider education initiatives to improve care and decrease cost and variation of care. Quality measures would be based on real world, evidence-based research. For instance, if the state found that only 50% of prescriptions for blood pressure medicine were filled, then an intervention to improve use of prescribed medicines may be appropriate. Such a finding could also be paired with stroke rates (from the Hospital discharge database). If stroke rates were found to be higher in counties with lower blood pressure medication filling rates, the finding could lead to targeted interventions to improve health equity.

In addition, an APCD allows researchers to provide a snapshot of a community’s needs by assessing the prevalence of chronic diseases. It could also describe trends in spending for chronic diseases and the attendant risk factors. In Oregon, the Oregon Health Authority Division of Public Health is reviewing claims data to understand the “magnitude and determinants of antibiotics use” in the state and to “inform policy discussion and education programs to decrease unnecessary use.” They seek to reduce antibiotic resistance and will use the data to estimate the proportion of outpatient cases of certain respiratory infections that receive antibiotic prescriptions. These are only a few examples of the many analyses and interventions that are possible with comprehensive claims data.

**The Value of an APCD for Health Systems and Providers**

Health systems and providers can benefit from an APCD by using claims data to evaluate trends in patient resource use and common practices. These can serve as indicators of quality, cost drivers, and population health trends, and can be used by health systems to compare themselves to others on both the state and national level.

d Fostering Health North Carolina is a project of the North Carolina Pediatric Society, with support from The Duke Endowment and the North Carolina Department of Health and Human Services.

How Health Systems and Providers are Using APCD Data

Hospital readmission rates are viewed as an indicator of quality. However, providers and health systems often only have access to their own patient records. This means that they can assess how often a patient visits their own hospital or an office within their system, but not how many other facilities that patient has visited that same month or year. APCDs could be used to determine trends in utilization across a spectrum of care settings. APCD data can answer questions such as, “Did a patient visit a primary care provider prior to their first hospital admission?” They can also provide information on post-admission care in a patient’s home community.

Figure 1. Readmissions, All Cause 30 Day (per population) for Arapahoe, Denver, and El Paso Denver Counties Compared to the Colorado State Average in 2014

<table>
<thead>
<tr>
<th></th>
<th>Arapahoe</th>
<th>Denver</th>
<th>El Paso</th>
<th>State</th>
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<tr>
<td>Completeness Score</td>
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<td>C3</td>
<td>C3</td>
<td>C3</td>
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<td>Illness Burden Score</td>
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<td>0.79</td>
<td>0.87</td>
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<th>Index</th>
<th>Value</th>
<th>Index</th>
<th>Value</th>
<th>Index</th>
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</thead>
<tbody>
<tr>
<td>All Cause 30 Day Readmissions Per Thousand Per Year</td>
<td>1.7</td>
<td>1.13</td>
<td>1.4</td>
<td>0.93</td>
<td>1.4</td>
<td>0.91</td>
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<tr>
<td>Percent of All Cause 30 Day Readmissions by Service Line</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>Behavioral Health</td>
<td>3.90%</td>
<td>0.98</td>
<td>3.47%</td>
<td>0.87</td>
<td>1.61%</td>
<td>0.41</td>
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<tr>
<td>Cardiology</td>
<td>8.23%</td>
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<td>6.93%</td>
<td>1.10</td>
<td>4.84%</td>
<td>0.77</td>
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<tr>
<td>Gastroenterology</td>
<td>8.23%</td>
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<td>6.44%</td>
<td>0.59</td>
<td>18.55%</td>
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<td>General Surgery</td>
<td>10.82%</td>
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<td>1.17</td>
<td>10.48%</td>
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<tr>
<td>Neonatology</td>
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<td>5.45%</td>
<td>2.07</td>
<td>1.61%</td>
<td>0.61</td>
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<tr>
<td>Neurology</td>
<td>6.93%</td>
<td>1.18</td>
<td>6.44%</td>
<td>1.10</td>
<td>4.03%</td>
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<td>Orthopedic Surgery</td>
<td>6.93%</td>
<td>1.08</td>
<td>2.48%</td>
<td>0.39</td>
<td>6.45%</td>
<td>1.00</td>
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<tr>
<td>Other</td>
<td>0.00%</td>
<td>0.00</td>
<td>1.98%</td>
<td>2.70</td>
<td>0.81%</td>
<td>1.10</td>
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<td>Other Medical</td>
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<td>31.19%</td>
<td>1.00</td>
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<tr>
<td>Other Surgical</td>
<td>2.16%</td>
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<td>2.48%</td>
<td>0.78</td>
<td>4.03%</td>
<td>1.27</td>
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<tr>
<td>Pulmonary</td>
<td>8.23%</td>
<td>1.26</td>
<td>3.96%</td>
<td>0.60</td>
<td>8.06%</td>
<td>1.23</td>
</tr>
<tr>
<td>Urology/Nephrology</td>
<td>3.03%</td>
<td>1.03</td>
<td>2.97%</td>
<td>1.01</td>
<td>0.81%</td>
<td>0.27</td>
</tr>
</tbody>
</table>

A pound sign [#] indicates that the actual data was suppressed due to small membership at this time. A dash [-] indicates that the index was not calculated due to suppression of the value. Values highlighted in red and green indicate noteworthy results above or below the statewide average.


Figure 1. Data Notes

**Value** represents the utilization for the indicated group

**Index** compares measure values for a specific geographic region to the state wide average (represented as 1.0). An index above 1.0 means the measure is higher than the state average, and below 1.0 is less than the state average. For example, an index of 1.11 is 11% above the state average, and an index of .83 is 17% below the state average.

**Data Completeness:** The Data Completeness Score is an indicator of how many people in an area are actually submitted by an insurance payer within the APCD data. Quartile categories are used to describe this completeness with scores ranging from C1 to C4 with C4 being the most complete. Lower scores indicate a greater degree of caution should be used in data interpretation.

**Illness Burden:** The Illness Burden for a population is a number used to measure the relative health of that group based upon the number and types of healthcare services used. A higher number indicates that population uses more and/or costlier services and is typical when a greater portion of the group has chronic disease. Likewise, smaller numbers (those below 1.0 - the average), indicate a healthier population using less services.

Understanding these trends not only helps a health system or provider evaluate their own quality of care, but can also help control health costs for the community and the state by identifying preventable admissions and readmissions. In Colorado, aggregate claims data are available online to enable analysis on the causes...
for readmission within 30 days, either by county, health statistic region, or the first three digits of a zip code. Figure 1 is an example of how readmission data are made available from the APCD in Colorado. The data can be customized for a variety of users and analyses. This is a valuable tool for health systems that are penalized for readmissions.

In Maine, a hospital is using claims data for strategic planning; they want to determine patient origin and market share. By analyzing service line trends and assessing utilization patterns, they hope to understand patient demand and future resource needs. In Oregon, researchers are using the state APCD to determine the amount of primary care spending in the state. The report will detail the primary care spending by payer, and will show the percentage of total spending that is allocated to primary care. The goal of this statutorily mandated report is to assist policymakers in understanding the resources that are allocated for primary care and to support a collaborative that assists primary care providers. Oregon claims data is also being used to evaluate quality of care due to integration of behavioral and physical health care. The goal of the research is to develop metrics to track integration claims data and identify best practices.

An APCD can also be used to allow hospitals to benchmark cost of care and patterns of utilization compared to averages in the state. For example, an APCD could release to each hospital a complete description of cost of care for each procedure and diagnosis-related group, with a comparison to statewide averages. Similarly, an APCD could share information on care utilization, such as post-stroke rehabilitation (e.g., physical therapy, occupational therapy, skilled nursing), and compare the system’s utilization patterns to statewide averages. Using these data, a hospital system can evaluate the cost and care utilization patterns by service line in comparison to averages of peer institutions. This information can lead hospitals to identify expensive or inefficient service lines and design new care pathways to improve efficiency. Also, an APCD can streamline filing and synthesis of post adjudicated claims from insurers.

It is important to note that hospitals already have access to claims data that they submit for payment. In addition, due to contractual relationships with insurers, health systems generally have access to post adjudicated claims in a relatively short time frame. Large health systems also have the analytic capability to study utilization patterns and trends for the purpose of health system planning. Health care systems and providers are appropriately cautious about sharing data that may violate patient confidentiality law or contracts with payers. It is important that antitrust concerns are addressed when considering data requests; providers and health systems may need all of their own data, but they do not need all of their competitors’ data. Administrator of the Colorado All Payer Claims Database (APCD There is value to health systems and providers seeing where and what care patients receive in the state without necessarily receiving information on the cost of the care in a specific health system.

The University of Michigan is collecting claims data from Medicare, Medicaid, Blue Cross Blue Shield of Michigan, and Blue Care Network of Michigan. The initiative, called the Michigan Data Collaborative, also collects data from databases, including registries, immunizations, and self-reported data, in order to build a broad, multi-payer claims database that incorporates other datasets as well as claims data. The reports can be used to benchmark performance, identify opportunities for improvement, and assist in identifying high risk and at-risk patients. The collaborative releases reports on quality and utilization performance, feedback on the associated population for use in care management, and incentive payments. This is an example of a regional claims database with powerful opportunities for quality improvement. An APCD designed with antitrust concerns in mind could replicate this opportunity on a broad scale for the health systems in a state.

The Value of an APCD for Employers

Health care costs are a top concern for employers. According to a recent poll, 90% of chief financial officers said that if health care costs were lower, they could invest more in their business. In 2016, the North Carolina Chamber of Commerce chose health care as an advocacy issue and is currently striving to make North Carolina a top ten state for health and health care value. Currently, North Carolina is ranked 32nd in the nation. A preliminary report entitled Roadmap to Value-Driven Health reviews the current state of health in North Carolina and defines the North Carolina Chamber of Commerce’s Vision for North Carolina in 2030. The report identified population health as an important area for improvement and imperative to creating a strong business environment.

Also critical for employers is the cost and utilization of health care by their employees and covered spouses and dependents. Employers need cost information, which an APCD can provide, in order to both understand and evaluate how to decrease expenses. According to a recent poll of 100 chief financial officers at large self-insured US companies, “80% say they feel powerless when it comes to managing their company’s health care spending.” An APCD would not, on its own, decrease an employer’s costs, but by benchmarking one employer’s health care costs with another’s, it may allow for the identification of best practices. In addition, this data could inform employers on the impacts of plan changes or benefit changes. If an employer eliminated...
dental benefits, for example, they could evaluate how the health and health care expenses of their employees are impacted. Currently, some of this work is done by insurance agents and benefit consultants in comparing products for employers. However, as employers move from one payer to another, the need to compare insurance benefits and products across payers becomes more acute. Further, employers or organizations that represent them could access this data to understand consumer behaviors that drive cost. This will allow employers to design workplace programs and benefit packages that more effectively limit the growth of cost. Also, as state policymakers measure and manage the total cost of care, quality of care, and ultimately the health of an entire state, an APCD adds to the opportunity to make a state more attractive for business investment.

**How Employers are Using APCD Data**

An APCD can help employers understand their employees’ health needs and how these compare to the rest of the population. For example, in 2014, Maryland enacted extensive changes to their health care system; major provisions of the Affordable Care Act were implemented and the new state-based insurance exchange was established. This led to important changes in the individual insurance market. To understand the impact of these changes, claims data were analyzed for information on spending and use among privately insured citizens. The analysis found that between 2013 and 2014, the number of members in Maryland’s population aged 64 and younger who were privately insured and in the individual market increased by 26%, that the cost per member per month increased by 31%, and that utilization increased across all service categories. In spite of the increases, however, the privately insured individual market had the lowest per member per month spending. The report also found that the per member per month spending for all services in the small employer and large employer market remained largely unchanged for the large employer market and decreased for the small employer market. The per member per month spending in patient services decreased for both of these markets.10

In Maine, researchers are looking to better understand health care costs and their relation to specific diagnoses in order to support the growing self-funded insurance industry. Researchers want to understand the cost trends for high-cost diagnoses and believe that by analyzing claims data, they can assist payers with setting premiums that more accurately reflect actual outcomes and costs.21

APCD data can also be used by employers to inform their employees about cost and quality of care. For example, in Colorado, claims data were analyzed and showed that freestanding emergency departments had higher costs than urgent care centers and gave employers information to educate their employees on the differences and costs associated with freestanding emergency departments versus urgent care centers.30 Initiatives like this have the potential to save the employer money by encouraging employees to seek out not only the best cost of care, but also the highest quality of care that may prevent future utilization. Thus, APCD analyses can equip employers with information so that they can encourage and educate their employees to utilize certain aspects of health care over another.

**The Value of an APCD for Payers**

Public and private payers can utilize APCD data to analyze health needs of the population, utilization of services, and costs compared to other plans’ populations, in order to develop quality measures, analyze geographic variation in health care, and analyze episodes of care in order to create bundled payments.31 In Oregon, researchers are using the claims data to compare real-world pharmaceutical usage with clinical trials in order to help insurers establish better priced drugs.17

Overutilization of services can be an important area for an APCD to deploy analytics and care management resources. For example, a study by Community Care of North Carolina demonstrated some effect of an education-based intervention targeting individuals with ten or more CT scans in the last year.32 One of the limitations recognized in the study was the large number of people that enter and exit Medicaid in a given year. This impacts all payers, and understanding utilization across payers could benefit payers, consumers, and decrease the total cost of care in North Carolina.

Increased payer reporting burden is a potential cost of an APCD. Reporting structures that are not connected to data that payers actually collect and reporting structures that change frequently can lead to increased payer reporting burden. However, there is some evidence that APCDs could ultimately reduce reporting burden of insurers. For example, Massachusetts is offsetting the payer burden by allowing data from the APCD to replace some existing required plan filings.14
Depending on the data release rules of a state, a payer can benefit from an APCD in a variety of ways. APCDs give payers a way to benchmark their own performance against competing commercial payers and against public programs. Payers can also use APCD data to get a wider look at spending and provider practice trends across the state. Lastly, if health systems, state policies, and consumers can improve efficiency in health care utilization (higher value and/or lower cost) this would benefit payers.

It is important to recognize that payers, like health systems, have extensive health care data on their covered beneficiaries and are already engaged in analysis and programming to improve the health care efficiency of the beneficiaries that they cover. For example, insurers are already actively involved in analysis of beneficiaries that use the emergency department frequently, are subject to re-admission, get repeat high end imaging, or otherwise consume a large volume of services. These individuals may be offered care management services in an effort to improve the efficiency of care. An advantage to using an APCD for some payers may be to understand utilization as beneficiaries move on and off a health plan—and thus capture charges for an individual across time and payer. Also, insurers with smaller market share may benefit from an understanding of cost in a marketplace beyond their consumers. However, insurers do incur significant time -600-800 hours on average for each platform and business area- in preparing and submitting data for an APCD. Further, insurers, like health systems, need to assure adherence to federal confidentiality law and respect proprietary contracting between insurers and providers of care. This can be achieved through appropriate APCD design.

The Value of an APCD for Consumers

Consumers can also benefit from an APCD. A New York study found that consumers are looking for health care information about their provider networks, formularies, insurance product value, provider procedure price, provider quality, and provider value. New Hampshire and Maine have created consumer websites for reviewing price data and provider value. These two sites, nhhealthcost.org and comparemaine.org, are models for other states considering consumer transparency aspects for their APCDs.

The New Hampshire model, Health Cost, was launched in 2007 and includes information on 30 common services. Most of the services are outpatient, with the exception of childbirth. Health Cost reports the median total amount paid for each service, including the facility and provider payment. The cost reported on the site is the average payment to the provider for that procedure, calculated from the claims data in the APCD. The Maine model, CompareMaine, provides average cost and quality information on over 230 health care procedures from over 270 facilities in Maine, drawn from the Maine APCD. The average cost amount represents both the amount that the insurer paid and the patient’s expenses. The quality information is compiled from patient survey ratings in the Hospital Consumer Assessment of Healthcare Providers and Systems (CAHPS), the Alliance Health Project, Clinical & Group CAHPS, and Patient-Centered Medical Homes CAHPS as well as the Preventing Serious Complications measures and the Preventing Healthcare-Associated Infections measures. The Preventing Serious Complications measures use eight Patient Safety Indicators from the Agency for Healthcare Research & Quality. The Preventing Healthcare-Associated Infections measures that are used on comparemaine.org come from the federal Centers for Disease Control and Prevention. This site reports the rating using the Standardized Infection Ratio that adjusts for the characteristics of hospitals and patients. The comparemaine.org website shows, for example, that the price for surgical arthroscopy of the shoulder can range from $7,925 to $23,274, with an average price of $12,270. The price for surgical arthroscopy of the knee can range from $4,533 to $13,877, with a state average of $6,625. These price transparency tools are valuable because they can inform consumers about average costs and quality of common procedures in their area, empowering them to make better health decisions.

Many insurers offer price transparency tools. Some include information on prices specific to the policyholder, incorporating his/her specific plan and deductible information. A price transparency tool offered by an insurer may be more helpful to the individual than a state-based model that does not incorporate individual plan information. In addition, consumers may require education on the usefulness of these tools; a 2013 report revealed that 98% of health plans offer or support cost calculator tools, but only 2% of their members use them. State-based APCDs may be more useful for consumer advocacy groups and employers to use data and analysis to drive care and also offer information about variation across the state.

The Value of an APCD in Identifying Fraud, Waste, and Abuse

Claims data can also be used to analyze practice patterns and identify outliers. The North Carolina Dental Society is involved in an initiative to monitor claims data of over 154,000 dentists in the United States, analyzing more than 1.8 billion records. The standard deviation is determined by running approximately four hundred algorithms. By monitoring the claims, the North Carolina Dental Society and their partner, P & R Dental Strategies, identify dentists who have unusual billing patterns and focus on those practices for additional education on

how to appropriately file claims. The North Carolina snapshot showed that 950 dentists were considered outliers and required focused review. Some outliers may be disqualified from participation in networks, others may have lower reimbursement rates, and others are disclosed to the Board of Examiners for legal action. The initiative helps self-regulate the dental profession and provides quality assurance to individual dental practitioners.38

This initiative is an example of how claims data can be analyzed to determine normal and identify abnormal practice patterns. Analyzing claims data to establish baselines allows for the spotting of unusual billing and an opportunity for training, or reporting for fraud or abuse. Payers already do this work, but an individual payer will have data limited to claims from that payer. An APCD could detect abuse or excessive billing distributed across payers that may be more difficult for an individual payer to identify.

Claims data can also identify areas of efficiencies within a health system or of a payer. Elimination of waste within a health care system is of tremendous value to all users. In Oregon, claims data is used to ensure that invalid Medicaid claims are not paid, by identifying plan members with unreported third-party insurance. This streamlined method allows the Medicaid Management Information system to stay updated by contacting other insurers or pharmacy benefits managers to obtain the policy information.17 At the national level, public and private payers are pooling claims data to identify suspicious billing. This initiative, called the National Fraud Prevention Partnership, requires public and private payers to submit claims data and share the tools they use to detect fraud.39

As demonstrated above, claims data provide important information on the utilization and cost of health care in a state. It is difficult to manage the costs of health care if there is no readily available way to measure the cost of health care. Collecting claims data in an APCD would provide information for policy makers, employers, health systems, payers and consumers, and researchers.

Recommendation 1: The North Carolina General Assembly should establish an All-Payer Claims Database (APCD). The goal of the database should be to improve the health of North Carolinians. Primary use cases include population health surveillance, research, and public policy analysis. However, the legislation, regulation, and design of the database should allow for flexibility for other uses as appropriate.

APCD Governance

The authority for an APCD is generally created through legislation, and the details of implementation are usually determined by a governing board. An APCD requires a governing board to create regulations, determine data submission and release guidelines, and handle the infrastructure and maintenance of the database.

Governing Board

Governing boards for APCDs vary from state to state, but most boards include representation from health care stakeholders, including providers, consumers, employers, payers, researchers, and government officials. In other states, the governing board is usually appointed by a combination of statute, governor, general assembly, and organizational home. Arkansas, for instance, has four statutorily named members and nine governor appointed members.40 Colorado has directors of executive agencies, representatives from various private payers, and members appointed by the General Assembly—one appointed by the State Senate and one appointed by the State House of Representatives).41 Virginia, on the other hand, merely requests balanced representation of all stakeholders and public health experts.42

Data Access

In North Carolina, the governing board should be tasked with identifying the organizational home, claims and data submission layout, and supplemental funding. The governing board should create data release rules outlining which users will have access to the claims data. In order to access APCD data, states generally require the requesting entity to submit an application to the governing board. For example, the release of Colorado APCD data requires the multi-stakeholder Data Release Review Committee to review the data request and advise the administrator whether the request meets criteria as outlined in the Colorado Department of Health Care Policy and Financing rules. Two additional requirements include the strict enforcement of HIPAA privacy, and that the purpose of the data request meets the goals of the Triple Aim for Colorado. To receive data in Kansas, the requesting agency has to agree to supply the state with a narrative describing the results of the analysis done on the data provided. Massachusetts has separate applications for government and nongovernment requesting agencies. Their five-step nongovernment requesting agency process includes
submitting a data request, consulting with a technical specialist, formulating a data management plan, and undergoing a committee review.43

State rules for releasing certain data may depend on federal guidelines. For example, an APCD can only release Medicare data to certain qualified parties via a Qualified Entity (QE) or state agency data request rules.44 The APCD Task Force generally supports more users having appropriate access to the data. Access needs have to be balanced: an APCD needs researchers and analysts to have access to the data in order to maximize the opportunity for improving public health, efficiency, and public policy. At the same time, the data released to users must adhere to state and federal guidelines to protect health information, avoid antitrust concerns, and protect contracts between payers and providers.

Organizational Home

When determining an organizational home, the governing board should consider the technical expertise, data analysis capabilities, and strong security systems required of an APCD. In addition, if the APCD is hosting substance use claims, there are legal requirements that the claims data be housed within the state Department of Health and Human Services.9 Some states have placed their APCDs within Health Departments, the Department of Insurance, or the Department of Finance, while others have created nonprofit entities or independent government agencies to house the APCD.45

It is important that the governing board reflects the stakeholders’ and data users’ interests. The Task Force recommends replicating the model of the NC HealthConnex advisory board, and tasking the board with identifying an organizational home, creating regulations surrounding submission and release and infrastructure and maintenance, identifying supplemental funding, and addressing other issues as they arise.

Recommendation 2: The North Carolina General Assembly should create an APCD governing or advisory board that includes health care stakeholders. The types of stakeholders to consider include providers, consumers, employers, national and regional payers, public health professionals, researchers, representatives from NC FAST and the HIE, county social service workers, and others. The governing board should be responsible for making recommendations to the General Assembly regarding an organizational home, regulations surrounding submission and release and infrastructure and maintenance, identification of supplemental funding, and other issues as they arise.

APCD Participation

There are currently 22 states either with an existing APCD or in the process of developing one.9 Most of these states legislatively mandate participation in the APCD. A mandatory APCD allows for a uniform and comprehensive database. Voluntary databases may be incomplete because payers may choose not to submit any or all of their data. In order to create the most useful database, it is important that the database is mandated to ensure that all payers with a modest market share in North Carolina participate, submit data on similar timelines, and face penalties for noncompliance.33 Fines provide the legal channel for assuring compliance, but should rarely if ever be levied as long as payers make good faith efforts to comply with state statutes. One national payer reported to the Task Force:

UnitedHealthcare submits files to all statutory All-Payer Claims Databases. Each state has language to establish penalties for failure to submit data. UnitedHealthcare works closely with all of our vendors and state representatives in order to communicate if there are any unforeseen issues which are preventing timely submission of data. We find that states are willing to work with submitters, assist with issue resolution, and utilize penalties for flagrant violations of the requirements or nonresponsive submitters who fail to comply. It has been our consistent experience, that due to the very complex nature of All-Payer Claims Database submissions, the variability of businesses, information technology platforms, claims data warehouses, and other business impacts, states are willing to act as a partner with health plan submitters and are willing to assist in working through issues rather than use punitive steps such as penalties.4h

Recommendation 3: Where legally permissible, the North Carolina General Assembly should require payers who cover 1,000 or more individuals in North Carolina to contribute claims data to the APCD.

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g  Cooper, Joe. Chief Information Officer, Information Technology Division, North Carolina Department of Health and Human Services. Personal communication. Friday, January 26, 2017.
Funding for a state APCD can take a number of forms. In Delaware, the APCD is funded by grants or other independent funding sources. 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. Virginia receives a mix of funding from insurers, the Virginia Hospital and Health Care Association, and Virginia Health Information. Maryland is similarly funded from multiple sources, including payers, hospitals, health occupational boards, and nursing homes. 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. 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. One of the newer state APCDs, Tennessee, has an annual budget of approximately $500,000. A summary of internal cost estimates calculated the initial, first year cost of an APCD to be approximately $593,750. 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.

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. 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-making. When possible, the claims data from an APCD should be analyzed in conjunction with data from other sources.
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 “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” 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.55 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.56 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.\textsuperscript{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.\textsuperscript{56}

**Figure 2: Distribution of Insurance Coverage in North Carolina**

![Distribution of Insurance Coverage in North Carolina](image)


**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.\textsuperscript{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).

**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.”57 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.
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. 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. 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 wide-ranging liability.”

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. 

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.

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].”

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. 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. 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.

**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; 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.

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.
- 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.\textsuperscript{69}

An entity must apply for this designation and, if approved, is certified for three years. The entire process can take approximately 18 months.\textsuperscript{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.\textsuperscript{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.\textsuperscript{71} 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.\textsuperscript{72} 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.\textsuperscript{1} Multiple states, including Washington, Colorado, Utah, Maine, and Virginia, are using APCD Core, a standardized data layout.\textsuperscript{k} 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.\textsuperscript{73}

**Recommendation 8:** If feasible, the North Carolina APCD should adopt a standard data model.
An APCD increases the opportunity to improve quality of care, control cost increases, and minimize variations in care. All of these are of critical interest for state government, employers, insurers, providers, and the people of North Carolina. All-Payer Claims Databases (APCDs) can be used to inform public health and public policy priorities, evaluate the outcomes of public health programs and policies, determine the actual cost of health care in a state, provide consumer transparency, analyze geographic variation in health, and more.4-7

This task force report includes eight actionable recommendations to move forward towards the creation of an APCD. The recommendations from the APCD Task Force include information on the primary use cases for a North Carolina APCD, the governing and funding of the project, and the types of claims data that should be included in the database. These recommendations can guide the development of the APCD in our state in order to inform public health and policy priorities.

APCD DRAFT RECOMMENDATIONS

- **RECOMMENDATION 1**
  The North Carolina General Assembly should establish an All-Payer Claims Database (APCD). The goal of the database should be to improve the health of North Carolinians. Primary use cases include population health surveillance, research, and public policy analysis. However, the legislation, regulation, and design of the database should allow for flexibility for other uses as appropriate.

- **RECOMMENDATION 2**
  The North Carolina General Assembly should create an APCD governing or advisory board that includes health care stakeholders. The types of stakeholders to consider include providers, consumers, employers, national and regional payers, public health professionals, researchers, representatives from NC FAST and the HIE, county social service workers, and others. The governing board should be responsible for making recommendations to the General Assembly regarding an organizational home, regulations surrounding submission and release and infrastructure and maintenance, identification of supplemental funding, and other issues as they arise.

- **RECOMMENDATION 3**
  Where legally permissible, the North Carolina General Assembly should require payers who cover 1,000 or more individuals in North Carolina to contribute claims data to the APCD.

- **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.

- **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.

- **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.

- **RECOMMENDATION 8**
  If feasible, the North Carolina APCD should adopt a standard data model.
REFERENCES


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