

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.^h

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.

g Cooper, Joe. Chief Information Officer, Information Technology Division, North Carolina Department of Health and Human Services. Personal communication. Friday, January 26, 2017.

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

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