This Issue Brief provides highlights from a report outlining Mississippi’s options for implementing a statewide health data system. The report was commissioned by the Center for Mississippi Health Policy and prepared by the National Association of Health Data Organizations (NAHDO). The intent of the report is to facilitate planning and implementation decisions towards establishing a health data program in Mississippi. The complete report can be found at the Center’s web site: www.mshealthpolicy.com.

Mississippi is one of a very few states with no statewide hospital data reporting system, leaving significant gaps in information to guide policy and market decisions.

Figure 1: State Data Collection Systems

*Notes:
Due to lack of public funding:
ND has no continuous data collections.
KS, MN, DC have mandates to collect but collection is done voluntarily by the Hospital Association.

States with legislation/State agencies collect
States with legislation/Private agencies collect
States with no legislation/Voluntary collection
States with no statewide reporting systems
States have established hospital reporting systems to measure a variety of health status and health delivery system indicators:

- Injuries
- Hospitalizations for acute and chronic illnesses
- Diabetes amputations and other complications of poor blood glucose control
- Costs associated with preventable hospitalizations
- Maternal and child health status indicators
- Quality indicators for infectious and chronic conditions

Mississippians suffer from some of the highest death rates in the nation in several areas:

- Infant mortality
- Diabetes and heart disease
- Cancer
- Accidental injuries

In order to reduce mortality and disability, it is important to address the underlying factors that contribute to the problems. Comprehensive health data aid this goal by outlining where resources and programmatic activities can be directed to have the largest impact.

In addition, there is a public interest in ensuring that health care dollars are spent in the most effective and efficient manner possible. Health care spending in Mississippi is equivalent to eighteen percent of the gross state product and has been growing steadily at rates several times the general inflation rate. The largest portion of this money goes to hospitals, approximately $6 billion annually, and most of these dollars are from public funds, primarily Medicare and Medicaid.

A statewide hospital reporting program uses standardized information that hospitals generate for reimbursement, thus reducing the burden on hospitals to supply this information. Established state health data programs are willing to share their expertise and lessons learned with other states like Mississippi. State-developed software for editing, reporting, and web-based query of data are available at no to low cost.

**Structure**

- Statutorily mandate reporting of health care data, as 39 other states have done.
- Establish in the legislation stakeholder representation in the form of a data commission or committee with rulemaking authority.
- Create a health data program structure that is most likely to meet the objectives of public availability, sustainability of funding, equitable access, independence, and neutrality.
- Appropriate sufficient funding to support the implementation and ongoing operations of the health data system.

**Data Collection**

- Implement a hospital data reporting system in two stages, inpatient then outpatient, followed by other providers.
- Include key patient demographic data elements as part of discharge data requirements, but do not release any identifying information publicly.
- Identifiable information should be carefully regulated for authorized research and public health applications.
- Do not include clinical or laboratory data elements with initial inpatient reporting requirements, but assess for inclusion at later time as automation and standards evolve.
Data Standards

- Reference non-specific national standards for reporting requirements within legislation to permit flexibility as standards and information needs evolve.
- Administrative rules should specify core data elements that are aligned with national standards and serve to reduce provider reporting burdens.

Data Access and Dissemination

- During the planning phases, develop a data release plan and establish policies that support the plan. The plan should provide for the release of de-identified data in the form of a public use data set, controlled by a data use agreement, and the release of a research-oriented data set for bona-fide research and federal programs, either with Institutional Review Board approval or data policy board review.
- Price data products in a manner that balances the need for data sales revenues with data access for authorized uses.
- Provide for data access by authorized public health programs and support data linkage and integration to reduce the burden on providers who have been sending multiple reports to various registries and surveillance data bases.
- After at least three years operating a statewide data system, adopt a web-based query system developed and used by another state.

Privacy and Confidentiality

Privacy and confidentiality issues are crucial during development and operation of a state health data system. Proper design of the system will appropriately ensure patient confidentiality, as is accomplished with other public health data systems. All of the states with these systems have established a proven track record in providing useful information while protecting the confidentiality of the data: in more than thirty years operating health data systems, there has been no known breach of patient confidentiality.

Data Ownership & Control

The organization designated to serve as the data steward should be viewed as a neutral or independent entity that is credible and trusted by stakeholders. There are three organizational models in which state health data systems can be categorized:

- A public agency collects data under a legislative mandate (28 states);
- A private agency collects data as a delegated authority to the state (11 states); and
- A private agency collects data voluntarily (9 states).

In some states, a statutory committee or commission is authorized to establish data policies. In others, a data advisory committee may be appointed to recommend policy to another body that promulgates the rules and regulations.

Funding

Various factors determine the cost of implementing a statewide data system within Mississippi. Other states have structured health data programs as a reflection of the type of funding provided to establish and maintain such systems. Whether housed within an existing organization or a newly created entity, the cost for needed basics can be estimated based upon the experience of other states. All state health data reporting systems supplement their core funding with revenue from data sales, but these revenues do not accrue for at least one or two years and are not sufficient to support core operations.
NAHDO estimates funding requirements for year one planning at approximately $277,406; year two at $387,894 for implementation; and year three full operations costs of at least $401,295. Three funding avenues to generate needed dollars are compared in Figure 2.

Figure 2: Advantages and Disadvantages of Three Types of Statewide Health Data System Funding Mechanisms.

<table>
<thead>
<tr>
<th>Funding Mechanism</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>General Appropriations</td>
<td>Legislative accountability. Assures program continuity through mandate.</td>
<td>Competes with other budget priorities.</td>
</tr>
<tr>
<td></td>
<td>Assures hospitals will submit data. Support of the state behind the program.</td>
<td>Rarely sufficient to solely fund and maintain a data system.</td>
</tr>
<tr>
<td></td>
<td>Providers cannot use fee assessment to pressure legislators to kill program.</td>
<td>Often have travel and training moratoriums--difficult to maintain skills of</td>
</tr>
<tr>
<td></td>
<td></td>
<td>staff without travel to workshops, training and conferences.</td>
</tr>
<tr>
<td>Fee assessment on health systems,</td>
<td>Shared expense and accountability across the industry.</td>
<td>Subject to political pressure. Demands for special private tools to analyze</td>
</tr>
<tr>
<td>providers</td>
<td>More resources than generally found in state budgets--allows up-to-date software &amp; hardware. Providers tend to be more engaged with data and products.</td>
<td>data may be greater.</td>
</tr>
<tr>
<td>Private Funding (membership dues)</td>
<td>Not subject to political influence. The data program must remain relevant to the funders to survive.</td>
<td>Proprietary interests may override the public interest. Public access may be limited or restricted. Sustainability is dependent on member funding/value.</td>
</tr>
</tbody>
</table>