BEYOND HIPAA:
How Data Sharing Can Prevent Fraud in State Public Assistance Programs
Patient information is considered sacrosanct. It’s protected so fiercely — using the Health Insurance Portability and Accountability Act (HIPAA) as a compass — that even legitimate requests for information are sometimes denied.

There are countless examples of this. A caseworker from child protective services tries to get health information about a child from an agency in a neighboring state and is told the information is protected under HIPAA. A woman whose 85-year-old mother goes missing tries to give the local hospital her medical history in case she shows up in the emergency room. They refuse, declaring it a potential HIPAA violation.¹

These examples illustrate how HIPAA, enacted in 1996 to protect patients’ personal health information, has been subject to misinterpretation — or in many cases, over-interpretation — that limits information sharing and potentially prevents agencies from effectively serving their constituents.

If states shared data more freely, they could benefit in a critical area: program integrity. Improved program integrity would enable states to better manage public assistance programs, ensure they had the resources in place to support programs, and reduce and prevent fraud. To be able to do this, states must first gain a clear understanding of the law.

**Current Status of Data Sharing Among States**

Some state laws provide unclear parameters and context of what data can be shared with whom, why and when. Others have laws that may coincide with or may even be more strict than those set forth by HIPAA. Montana, as an example, has decided that HIPAA laws aren’t strict enough and has enacted additional protections. Health care information can only be shared with another state or public health agency when it’s necessary to provide health services to a patient.

Illinois provides an example of states on the opposite end of the spectrum. It has made open data a priority, including enacting “Patient Choice in Data Sharing” in 2013, an extension of HIPAA that clarifies the consent process for providers connected to the state health exchange. It also created the Health Information Exchange Authority in 2010 to implement policies and procedures that govern data sharing. Iowa allows information sharing² to improve medical management and to avoid duplicating services, while New Jersey enacted two separate laws that allow inter-agency data sharing to investigate Medicaid fraud and abuse and cross-state data sharing to realize efficiencies and cost savings. Ohio permits data sharing for the purposes of modernizing and streamlining health and human services programs.

Illinois, Iowa, Ohio and New Jersey can serve as models for the next steps in data sharing.

**Best Practices for Data Sharing Among States**

Once a state agency can share protected health information, the next step is to determine how. There are several options.

**Memorandums of Understanding**

States can create memorandums of understanding (MOUs), sometimes called memorandums of agreement (MOAs), to establish procedures, privacy requirements and protections for data sharing between themselves and other entities. These agreements typically include details about the scope of the data, how it will be used, constraints on this usage and how the data will be protected. These documents often outline federal regulations that permit data sharing for certain purposes, but may include state specific laws as well. States need MOUs or MOAs to set clear parameters of appropriate use cases and define the responsibilities of all parties involved to establish clear liability.

**Governance Councils**

Best practice oversight of data sharing initiatives recommends the establishment of a governance council for the proper administration and management of all activities. This body provides oversight and acts as a decision-making entity that aids the project in achieving its vision. Multi-state governance council models require obtaining and retaining commitment during key phases of project activities, including but not limited to: initial commitment, planning, procurement, development, implementation, operations, maintenance and communications. During these phases, the governance council is responsible for coordinating

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¹ The nuances of state law — and HIPAA rules — arguably make it easier not to share data out of fear of reprisal. However, it’s critical that states understand HIPAA exceptions and develop a safe and effective framework for data sharing.

² While this information is clearly outlined on the U.S. Department of Health and Human Services website, comprehension may be a matter of interpretation. Under the HIPAA Privacy Rule, a covered entity (including health care providers, health plans and health clearing-houses) and their business associates can disclose protected health information with other covered entities if:

- Each entity has a relationship to the patient and the information pertains to this relationship
- The disclosure is for a “quality-related health care operations activity”
- The disclosure helps detect health care fraud, abuse or compliance

This data can include medical records, administrative data, information on health status, treatment, child abuse and neglect, or domestic violence. HIPAA also covers other exceptions for data disclosure, including for public interest and benefit,³ for research, to improve health care operations and to detect fraud and abuse. However, covered entities must develop policies, procedures and a minimum necessary standard to share private health information. Patient consent is optional, but state agencies can voluntarily choose to seek it.

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the necessary stakeholders for participation and for taking their needs and expectations into account at the state, federal, regional and solution-provider levels.

**Interoperability Resources**

The National Human Services Interoperability Architecture (NHSIA) has a proposed framework states can use for data sharing to prevent fraud and optimize the delivery of social services. The Administration of Children and Families (ACF) and Health and Human Services also provide an interoperability toolkit to help states navigate data sharing and understand changes in law that facilitate more collaboration.

**Best Practice Case Study**

Many states have been able to realize the benefits that can be attained through data sharing initiatives. The National Accuracy Clearinghouse (NAC), a consortium of states that include Alabama, Georgia, Florida, Louisiana and Mississippi, came together to share data on benefits program applicants to identify and prevent dual participation in real time. The NAC improves service delivery, application processing accuracy, state efficiency and data integrity, and expedites interstate coordination and investigation. Originally piloted for the Supplemental Nutrition Assistance Program (SNAP), the NAC has expanded to include Medicaid, Temporary Assistance for Needy Families (TANF), the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), and other public assistance programs. Fraud is an issue that plagues all health and human services programs. Dual participation — where a single individual seeks multiple sets of benefits either within or across state lines — is a key example of this. Sometimes these individuals are found to have moved and failed to notify anyone, but often these individuals have altered their information, provided false information or created an identity to receive benefits. So far, the NAC has reduced dual participation by at least 70 percent in each state, realizing an overall savings of $5.6 million in prevention just during its first year of pilot (May 2014 to June 2015). This initiative shows how impactful multi-state data sharing and their accompanying systems can be to minimize program vulnerabilities while freeing up resources for the beneficiaries who actually need them.
Conclusion

Data sharing is critical to fostering greater collaboration among states and identifying inefficiencies, duplications and outright fraud that shake the public’s faith in benefits programs. For too long, misinterpretation of HIPAA has prevented information sharing that could improve the delivery of social services. States must understand the law, which will allow them to act on exceptions when warranted and create appropriate frameworks and systems for data sharing. We often focus on policy reform and technological innovation to improve service delivery and eliminate fraud or abuse — spending millions of taxpayer dollars in the process — when there’s a more straightforward solution: using the data we already have. As Karen DeSalvo, national coordinator for Health Information Technology, said at a recent conference: HIPAA should not be “an artificial barrier to data flow.” Greater clarity around the law will ensure that it isn’t and pave the way for more initiatives like the National Accuracy Clearinghouse that empower data sharing for the greater public good.

Endnotes