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Health Care Information Technology: Getting the Policy Right

Edmund F. Haislmaier

While health care transactions generate an enormous volume of data, too much of it is disjointed and inefficiently used. Recent studies indicate that better management and use of this information could generate tens of billions of dollars in savings, reducing administrative costs while improving medical care. Many legislative proposals are based on the premise that benefits and savings will flow automatically from government-mandated ‘standardization’ and ‘interoperability.’ However, these technical concerns are secondary to creating a market framework for medical information. With that in mind, Senator Sam Brownback (R–KS) and Representative Paul Ryan (R–WI) recently introduced the “Independent Health Records Bank Act” (S. 3454 and H.R. 5559). This legislation would establish health care information record banks designed to protect patient privacy and respect the information ownership rights of patients and providers alike.

The Key Issues. Standardizing coding and billing, securing software, and ensuring hardware interoperability are merely technical issues. Far more important are the policy issues. These include the ownership of health care data, the way in which the value of the data is monetized, the mechanisms in place to protect patient privacy and confidentiality, and ultimately, the ways in which information technology (IT) policy can improve patient care. Four issues are central:

- *Ownership of Health Care Data.* Medical data is created by an interaction between a patient and a provider. Patients who don’t see providers don’t

generate medical data, and neither do providers who have no patients. Because data is generated only by a patient-provider interaction, the most reasonable legal approach is to recognize both parties’ claims to co-ownership of the resulting data. If other parties, such as a payer, are involved, then they too have a reasonable claim to ownership of that portion of the information that is generated by their involvement.

With clear ownership rights, it becomes possible to devise arrangements by which the owners can transfer those rights. The design of a system for aggregating, managing, and using medical data should be governed by a legal structure which recognizes that virtually all health system data is ‘co-owned’ by two or more parties. This structure must specify each party’s ownership rights and establish norms for owners to jointly exercise their ownership rights.

- *Monetizing the Value of the Data.* The potential of health information to be aggregated and analyzed in ways that increase efficiency and improve quality is underutilized. To remedy this, policymakers must first address the ways to establish the value of the data. The best solution is to create markets in which data can be shared,

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bought, and sold. Markets reveal the true value of data through the prices agreed to by willing buyers and sellers.

The set of rules governing markets for health care data should be simple and straightforward, allowing the value of the information to be priced through voluntary, private transactions between buyers and sellers that express 'natural' price levels, and still respect and enforce the legal co-ownership rights of the data's co-creators. Only with the right structure for valuing and trading health information can the latent value of that information be translated into hard dollar figures. Absent the right market design, the projected benefits will not be realized.

- **Protecting Patient Confidentiality.** Medical data comes wrapped in issues of privacy. The design of any health information system must include mechanisms that recognize and accommodate legitimate privacy concerns. The standard political response is to draft complex sets of formal rules. But the more complete and detailed the rules, the less flexibility there will be. The risk is bureaucracy and paralysis.

However, if privacy concerns are viewed as an extension of ownership issues, a more flexible and dynamic system becomes possible. The system for waiving inherent privacy rights would be part and parcel of the system for exercising ownership rights by granting others permission to use the data and can vary based by the transaction. For example, the more detailed the information that is sought about a patient, then the more explicit the patient's grant of permission would have to be, the higher the price for the data, and the larger the share of the proceeds credited to the patient's account. Thus, patients will have the opportunity to determine for themselves whether it is worthwhile to waive their privacy rights in exchange for exercising their ownership rights. The same would apply to providers with respect to data requests that focus on provider practice patterns.

- **Improving Patient Care.** Better use of medical data can improve patient care in three broad areas: clinical treatment, medical research, and

public health. In the clinical setting, better use of medical data can reduce administrative overhead, achieve operating efficiencies, help to identify, propagate, and continuously update treatment 'best practices,' and further improve patient outcomes through better care coordination and more appropriate medical interventions. In medical research, data analysis is the foundation that underpins advances in knowledge and improvements in technologies and treatments. Governments also have an interest in better data due to their public health responsibilities, such as tracking and responding to communicable diseases, conducting epidemiological studies, and measuring and monitoring safety issues attendant to the use of medical products. Given the government's roles as a payer for medical treatments and a funder of medical research, better data can inform public decisionmaking in those areas too. For policymakers, the test should be whether a proposed system will permit all stakeholders to easily access the data they need to realize these potential benefits while still respecting ownership and privacy.

Creating Neutral Independent Health Record Banks. The Brownback-Ryan legislation would address these four crucial policy issues through the creation of Independent Health Record Banks (IHRB). IHRBs would be neutral intermediaries responsible for collecting and managing medical information in accordance with rules and procedures that respect the ownership and privacy rights of patients, providers, and payers. At the same time, IHRBs would give medical information consumers a place to purchase accurate data for a variety of beneficial uses. Their independent, neutral status would enable IHRBs to avoid the inherent conflicts and concerns raised by alternative proposals that would vest control over medical information in only one set of stakeholders, such as providers, patients, payers, or government entities.

IHRBs would be private entities under regulatory oversight and would be member-owned, like credit unions or mutual insurance companies. Patients would be the member-owners, with providers and payers granted associate status, with specified rights and privileges. Interactions between the banks and

their members and customers would be governed by a set of standard contracts. The financial benefits derived from sales of IHRB data would be passed back, after deducting operating expenses, to the data owners.

This inclusion of an explicit mechanism for monetizing the value of medical information and passing that value back to the data owners is a major advantage of the Brownback-Ryan approach over competing proposals. The best way to induce patients and providers to share the individual data they create is to help them unlock the value of that data and share in the benefits derived from letting others use it.

For the patients who are member-owners, the resulting revenues would be credited to their individual accounts, the same way a credit union credits member accounts with interest payments based on each members' deposits, which in turn fund the loans and other investments that generate revenue for the credit union. Members could periodically withdraw accumulated funds to use for their own purposes. Making those earnings tax-free, as the Brownback-Ryan legislation proposes, would further induce patients to participate and agree to allow their data to be used for legitimate purposes.

For the providers and payers that would both contribute data and 'withdraw' data, the IHRB would maintain accounts that are credited and debited based on a schedule of prices for various information 'deposit' and 'withdrawal' transactions, with periodic cash settlements of their accounts. Other entities, such as researchers, would pay the IHRB to access data.

As a general rule, the more extensive the data request, in terms of the comprehensiveness of the records, and the higher the level of patient or provider permission required to authorize the information's use, then the higher the unit price the user should pay and the larger the share of the proceeds that should be credited directly to the owners' individual accounts. For example, a researcher may request the detailed medical records of 5,000 patients treated over the past three years for both

diabetes and hypertension. Of necessity, this information request is comprehensive and intrusive and so requires more explicit permissioning and greater privacy safeguards. Consequently, it should command a higher price, and more of the proceeds should flow directly to the affected patients and providers. Conversely, less extensive data requests with fewer privacy issues would cost less and could fund a general IHRB account that, after expenses, would be paid equally to all members as a general dividend.

Government health insurance programs should participate in IHRBs on the same terms as private payers. Government agencies conducting health or medical research or tasked with public health responsibilities should be treated the same as other private, third-party information consumers, such drug or device companies or academic researchers, and pay market prices for the data they need.

Conclusion. The potential benefits of improving America's health information system are substantial. But they won't be realized if policymakers don't first craft a policy framework that addresses the concerns surrounding the use of health information. Technical issues are secondary to these policy concerns. Putting the health IT "cart" before the market "horse" will result in a huge expenditure of time, money, and effort on just the latest failed health policy fad.

Too many lawmakers are reaching for the tools they know best—government programs and federal regulations—without stopping to consider whether these are the right tools for the job. Policymakers should maximize market incentives and innovation in this complex and rapidly advancing field, while preserving the legitimate interests of doctors and patients alike. The Brownback-Ryan legislation accomplishes this and should be the starting point for any discussion of how to best improve the collection, management, and legitimate use of medical information.

—Edmund F. Haislmaier is Senior Research Fellow in the Center for Health Policy Studies at The Heritage Foundation.