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RESEARCH BRIEF



Coming down from the Tower of Babel

Studying the state of electronic health information exchange in America—and charting its course forward



These days, you can summon a private driver to your exact location in minutes with a mobile phone app, have conversations in real time with strangers around the world in 140-character bursts, and find arcane information in seconds.

So why can't your medical information be instantly available, in a secure and usable way, to any health care provider who needs to treat you?

It sometimes seems like healthcare is living in Dark Ages of information technology, despite laws passed in the last decade that have tried to pull it into the 21st century.

For the University of Michigan's Julia Adler-Milstein, Ph.D., this provides a rich opportunity to perform research aimed at understanding the current state, testing theories, and proposing solutions that future policy could address to ensure that health information is available whenever and wherever it is needed.

HITECH, the ACA, and beyond

President George W. Bush set a goal for health records to become electronic by 2014. In 2009, President Barack Obama signed the HITECH Act—for Health Information Technology for Economic and Clinical Health.

Both presidents saw the importance of harnessing the power of digital information and underlying digital infrastructure to guide the delivery of healthcare, and improve its quality and safety.

HITECH provided nearly \$30 billion in incentives to physicians and hospitals to adopt and use Electronic Health Records, or EHRs. By investing in new digital systems, hospitals and physician practices could recoup some of their spending through federal reimbursement.

Then, in 2010, the Patient Protection and Affordable Care Act was signed into law. The ACA increasingly standardizes healthcare billing and requires health plans to begin adopting and implementing rules for the secure, confidential, electronic exchange of health information. It also allows the federal government to incentivize population-based care.

Hitting the brick wall

The spread of EHRs is undisputed: 75 percent of hospitals and 51 percent of physician practices now have such a system. But, Adler-Milstein's research has shown, rural and small hospitals lag behind, suggesting a need

to expand federal efforts to help these institutions select, purchase, implement and successfully use electronic health records.

Even if a hospital or practice has an EHR, the information in those systems hits a virtual brick wall the minute it's needed by someone else.

The lack of ability to share records electronically is a key source of frustration for clinicians trying to transfer or refer patients for further care, or get information on patients they're treating who have been treated elsewhere before. And it could interfere with the ability of patients to get timely and safe care.

This frustrating situation stems from a lack of what's called "interoperability"—the ability of EHR systems to communicate with one another. The underlying barriers are not technical, but rather rooted in:

- Financial incentives
- Information governance
- Different, sometimes conflicting, state regulations
- Privacy concerns and
- Patient identification issues

Myriad issues in each of these domains have to be addressed in order for healthcare organizations to agree to share their data, and have the data successfully flow. In other words, Adler-Milstein says, the problem is that there isn't just one problem.

In fact, it won't happen until providers and policymakers address all of them. But without strong financial incentives to solve these issues, provider organizations have a hard time justifying the resources and effort needed to solve them. So, she says, it should be no surprise we are where we are.

The HIE movement

This is not to say that no HIE exists today. Around the nation, organizations have sprung up with a goal of bridging the distance between EHRs at different care settings.

But, says Adler-Milstein, this results in a patchwork in which some communities have a robust exchange while others have nothing.

With HITECH funding, many states built or expanded HIE infrastructure. The states that have broad participation are predominantly small states that have treated it like a public utility, such as Delaware and Maryland.



States that have left HIE to the market have made less progress, and faced difficulty identifying a sustainable business model. A key reason is providers are typically the ones asked to pay to support HIE efforts.

Yet payers and ultimately patients are the ones that realize much of the benefit from HIE. It is therefore puzzling that payers have not stepped forward to support HIE efforts.

As part of her research, has Adler-Milstein interviewed 18 diverse payer organizations to understand how they think about the value proposition from HIE. The main issue, she finds, is that the geographic area each payer serves doesn't align with the geography served by each HIE. Payers with state-level boundaries, such as Blue Cross Blue Shield organizations, have the most engagement, because they are most likely to find an HIE effort that aligns with their coverage area.

Info blocking looms large

While HIE efforts continue to chip away at the brick wall, Adler-Milstein and others in the field have raised the alarm about a phenomenon that threatens to build it back up—on purpose.

It's called information blocking, a practice thought to happen when providers or EHR vendors engage in business practices that intentionally interfere with needed electronic information exchange. This concept was brought into the national spotlight in 2015, with a Congressional call for a report on any intentional practices that inhibit sharing to benefit a provider or vendor.

Adler-Milstein feels some vendors and providers are engaging in clearly wrong behaviors—such as charging exorbitantly high rates for interfacing with a different vendor's EHR system. Another source of blocking comes from providers claiming that the HIPAA law, which has created a culture of protecting information, prohibits them from sharing information electronically. (When in fact, HIPAA was written in part to make health information more portable, in a secure way.)

Adler-Milstein's team is carrying out a survey to get broad perspectives on the extent to which information blocking is occurring and what kinds of policy strategies could address it, without impacting reasonable business practices.

As the country tries to speed up progress on the interoperability issue, the Senate HELP Committee and the Office of the National

Coordinator for Health Information Technology (ONC) have both called upon Adler-Milstein to advise on key issues. She serves on a task force assembled by ONC's Health IT Policy Committee (HITPC), and has testified in front of the Senate committee.

How to solve these problems?

With so many complex dimensions to achieving the goal of bringing health information exchange into the 21st Century, there's no one simple, elegant policy solution, Adler-Milstein says. Achieving meaningful interoperability will require a multi-pronged approach—and a lot of hard work.

Opponents of a national patient identifier—a unique ID for records—often cite privacy concerns. But Adler-Milstein notes that policymakers and the public don't realize that the alternative—and standard practice today—is to use other information like name, address, and birth date, which, if exposed, is much more likely to lead to identity theft.

More broadly, many hope that the weak incentives to-date to pursue interoperability will be strengthened by the Accountable Care Organization movement. ACOs should, in theory, present major opportunities to break down the brick wall, at least among hospitals, clinics, and other healthcare settings that participate in each ACO.

Ultimately, Adler-Milstein feels that targeted policy action on specific issues (such as inter-state exchange, HIPAA clarification, and more robust EHR certification) coupled with strong market incentives for broad-based information sharing will be the optimal solution.

About the researcher

Julia Adler-Milstein is an Assistant Professor at the School of Information with a joint appointment in the School of Public Health's Department of Health Management and Policy. She leads the Laboratory for Health Information Technology Impact, funded by federal and foundation grants. Dr. Adler-Milstein holds a Ph.D. in health policy from Harvard University. Dr. Adler-Milstein's private-sector experience includes positions at the Center for IT Leadership at Partners Healthcare in Boston and in the Health and Life Sciences Division of Accenture.

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