

US Regional Health Information Organizations and the Nationwide Health Information Network: Any Lessons for Canadians?

Denis Protti

The creation of regional clinical data exchanges (usually referred to as RHIOs) is a centrepiece of the US national healthcare information technology strategy. How well are they doing and what lessons can we learn that might be applied here in Canada?

Background and Definitions

There seems to be general agreement in the United States that a Regional Health Information Organization (RHIO) is a neutral, non-governmental, multi-stakeholder organization that adheres to a defined governance structure to oversee the business and legal issues involved in facilitating the secure exchange of health information to advance the effective and efficient delivery of healthcare for individuals and communities. The geographic footprint of an RHIO can range from a local community to a large multi-state region. As regional networks of stakeholders mature, they often find the need for a formal independent organizational and governance structure (i.e., an RHIO) with systems to ensure accountability and sustainability for the benefit of all stakeholders. Experts maintain that RHIOs will help reduce administrative costs associated with paper-based

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The terms *RHIO* and *Health Information Exchange* (HIE) are often used interchangeably though most would see HIE as a "concept" relating to the mobilization of healthcare information electronically across organizations within a region or community as opposed to an "organization." Typically, an HIE is a project or initiative focused around electronic data exchange between two or more organizations or stakeholders. This exchange may include clinical, administrative and financial data across a medical and or business trading area. HIEs may or may not be represented through a legal business entity or a formal business agreement between the participating parties.

Local Health Information Infrastructure (LHII) is a term occasionally used synonymously with *RHIO*. LHII was originally termed by the Office of the National Coordinator of Health Information Technology (ONCHIT) to describe the regional or local initiatives that are anticipated to be linked together to form an envisioned National Health Information Network (NHIN). The NHIN describes the technologies, standards, laws, policies, programs and practices that enable health information to be electronically shared among multiple stakeholders and decision makers to promote healthcare delivery. When completed, the NHIN will provide the foundation for an interoperable, standards-based network for the secure exchange of healthcare information in the United States.

The development of the vision of the NHIN began originally with the National Health Information Infrastructure (NHII) described more than a decade ago in the Institute of Medicine report *The Computer-Based Patient Record*. The original idea behind the NHII was that it would be an initiative set forth to improve the effectiveness, efficiency and overall quality of health and healthcare in the United States. This would be accomplished through a comprehensive knowledge-based network consisting of interoperable systems of clinical, public health and personal health information that would improve decision-making by making health information available when and where it is needed. These interoperable systems would use a set of technologies, standards, applications, systems, values and laws that support all facets of individual health, healthcare and public health.

The path toward reaching a NHIN is anticipated to be through the successful establishment of RHIOs. When completed, the envisioned NHIN will provide universal access to electronic health records. In 2004 – not surprisingly following a visit from British Prime Minister Tony Blair – President George Bush called for electronic health records to be widely available in the United States by 2014.

The federal government has launched initiatives to establish interoperability standards, examine variations in state privacy laws, conduct demonstrations of the NHIN and fund studies of areas such as strategies for state governments. Organizations such as the eHealth Initiative and the Markle Foundation have brought together the diversity of healthcare stakeholders and communities to share experiences, create tools and identify policies and steps that will facilitate the achievements to date.

RHIO Models and Data Exchange Architectures

To date, there have been three different approaches to RHIOs, namely: (1) federated – multiple independent enterprises in the same region exchange data, (2) centralized or co-op – multiple enterprises in a region agree to share resources and create a central utility and (3) hybrid – a region containing both federated and co-op organizations.

A federated architecture (decentralized) is an approach to the coordinated sharing and interchanging of electronic information emphasizing partial, controlled sharing among autonomous databases within an RHIO. In a federated architecture, independent databases (decentralized) are connected to share and exchange information. Components of a federated architecture represent the various users, applications, workstations, main frames and other stakeholder components in an RHIO. Each component controls its interactions with other components by means of an export schema and an import schema. The export schema specifies the information that a component will share with other components, while the import schema specifies the non-local information that a component wishes to manipulate.

A centralized architecture is an approach to RHIO data sharing and the interchange of electronic information emphasizing full control over data sharing through a centralized repository. Components in a centralized architecture refer to the Central Data Repository (CDR) and the requestor. The CDR authenticates the requester through a technological means, authorizes the transaction and records it for audit and reporting purposes.

A hybrid architecture is a combination of the two architecture types where various data transactions occur based on a decentralized or centralized models. For instance, an RHIO may have pharmacy transactions occurring within a federated model while lab data is shared through a centralized database. Providers in hybrid architecture may decide to share patient data through a CDR or through peer-to-peer means.

RHIO Track Record to Date

While the exact number of RHIOs is very uncertain, there are at least 100 to 200 such efforts across the country. The Indiana Health Information Exchange, Inland Northwest Health Services and HealthBridge in Cincinnati are often pointed to as the few RHIOs which are the most successful. They provide basic health data exchange services, as well as biosurveillance and outbreak detection services. The Indiana HIE is also developing other services such as appointment reminders, alerts about patients who need services and pay-for-performance measurement and reporting. It has not gone without notice that part of the Indiana's IHE success is that its president and CEO is also the director of medical informatics at the well-known and Davies Award-winning Regenstrief Institute – one the US leaders in well established and proven clinical information systems. Their clinical messaging service is one of the nation's best; 27 hospitals in Indiana and over 5,000 Indiana physicians are receiving, on average, one million messages each month, saving millions of dollars per year by eliminating duplicate tests and administrative costs.

However, as Miller and Miller reported in the August 1, 2007, issue of *Health Affairs*, the Santa Barbara County Care

Data Exchange – which was once one of the most ambitious and publicized US health information exchange (HIE) efforts – failed in December 2006 (Miller and Miller 2007). Eight years after its inception by means of grant funding, and several months after providing some data, the Santa Barbara Project shut down operations. Despite its developed HIE infrastructure, the lack of a compelling “value proposition” for potential investors was the main cause of the project’s demise.

Technology barriers were also a major stumbling block; from software development to creating workable interfaces, solving technical issues became a long process of trial and error. Liability stemming from technical issues became a major concern, as leaders tried to decide who was legally responsible for lawsuits stemming from data errors such as improperly exchanging private patient information. Leadership vision is critical to creating a successful HIE; in the case of Santa Barbara, this vision was decidedly lacking. In addition to the passivity that the grant funding promoted, the community did not have any prior experience in assembling or studying HIEs. Morale was another problem; apparently, “community fatigue” set in amid the project’s delays and vendor instability.

Even with fewer technology delays and more community leadership, Miller and Miller argue that other RHIOs may also stumble over HIE service-value propositions without some combination of grants, incentives and mandates that develop initial RHIO infrastructure and services and ensure provision of unprofitable yet socially valuable services. After more than a year and \$530,000 spent in planning, efforts to bring an RHIO to Portland, Oregon, were put on hold in August 2007. The Oregon Business Council, a coalition of 40 of the largest employers in the state, said work on the RHIO had been at a standstill since a May 15 meeting of the council’s Health Data Exchange Group, which was formed to oversee the planning.

At that meeting, the group agreed to a proposed governance structure for the RHIO, which was to provide an electronic look-up service for clinical messaging, including laboratory results, imaging, discharge summaries and dictated reports that would work across a metropolitan area of 1.2 million. But key participants backed away from a funding proposal contained in a business plan that showed that the RHIO would save the community – mostly patients and payers – an estimated \$17 million a year, but would cost participants in the RHIO \$3.4 million a year over a five-year budget period. In addition, the budget did not include what were expected to be in-house operating costs for participating hospitals of up to \$150,000 a year (Conn 2007).

RHIOs are not working, according to an October 2007 report from the Information Technology and Innovation Foundation which contends that the results of the NHIN initiative have been disappointing. “The strategy of building the network from the bottom up by establishing many regional health information organizations throughout the country is not working. The majority of RHIOs are financially unsustainable. In the absence of clear national standards for sharing medical data, achieving system interoperability for RHIOs has been difficult” (Castro 2007).

A late 2007 survey, funded by Harvard’s Program for Health Systems Improvement, reported that nearly a quarter of the 145 RHIOs were defunct. Only 20 initiatives were deemed to be of at least modest size and exchanging some clinical data. Only 15 RHIOs exchanged clinical data across a range of patient populations. “Establishing a successful RHIO is not only hard work; it’s expensive, with significant upfront costs. The current approach to establishing RHIOs tends to rely on small start-up grants with the hope that participants will be willing to pay the RHIO once data exchange is initiated.” The survey findings

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suggest that some RHIOs are struggling with the transition to self-sufficiency as eight of the 20 moderate size RHIOs reported that they continued to depend heavily on grants. In contrast, nine never received grant funding. Thirteen RHIOs said they collected recurring subscription or transaction-based fees from participants to stay in operation.


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One of the key barriers to HIE growth is the lack of trust across all stakeholders. There are separate and largely uncoordinated patient safety initiatives as well conflicts between value exchanges, data-reporting entities and confusing, duplicative and otherwise misaligned organizational purposes. On one hand, state-level HIEs report being preoccupied with efforts to ensure implementation and sustainability of core HIE services while on the other hand, they also relate concerns about moving into secondary use of data – such as that for quality and performance monitoring – without sufficient foundation and support. Barriers to adoption also include misalignment of incentives, doubts in small physician practices about the quality of electronic health records, lack of interoperability, required workflow changes and lack of an adequately skilled national workforce.


According to privacy groups such as Patient Privacy Rights, the RHIO business model requires that hospitals, insurers and employers exchange patient health information without consent from patients. “Microsoft was very receptive to concerns about the unchecked loss of consumer control of personal health information and the abuse of Americans’ rights to health privacy. Microsoft is the first major multinational technology corporation to collaborate with PatientPrivacyRights.Org and use the 2007 Privacy Principles created by the bi-partisan Coalition for Patient Privacy as the basis for the consumer controls of the health data stored in HealthVault.”

Despite the difficulties encountered to date, contracts totaling \$22.5 million have been awarded to nine health information exchanges to begin trial implementations of the NHIN. The contracts call for the creation of a secure foundation for basic health information exchange between select HIEs upon which more complex functions will be possible over time.

One of the nine is a Tennessee RHIO which will begin implementation of a health information exchange network across the Appalachian region of eastern Tennessee and south-western Virginia. CareSpark, a non-profit RHIO is constructing the first phase of its clinical information network, enabling the



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secure exchange of patient records among healthcare providers in its 17-county community, which serves 705,000 residents, 18 hospitals and 1,200 physicians. An independent information technology firm has been selected as the lead systems integrator for much of the infrastructure and provider connections within the network. The integrator’s tasks are to accelerate the move to electronic health records, facilitate secure health information exchange, automate administration for hospital providers and align IT investments with business requirements and manage these environments and the applications that sit within them.

In another state, the Louisiana Rural Health Information Exchange has selected several information system vendors to help it create a federated system to share electronic clinical information between community providers by March 2008. The RHIO will enable provider members of the Louisiana Rural Hospital Coalition to exchange data with the Louisiana State University Health Sciences Center in Shreveport. Seven of the 24 LRHC hospitals plan to participate in the first year of the initiative. The Louisiana Rural Health Information Exchange is being funded by appropriations made in 2007 by the Louisiana State Legislature.

Those who form an RHIO must overcome a series of technical and non-technical challenges, such as patient identification techniques, security, governance and privacy, that are formidable barriers.

From RHIO 1.0 to RHIO 2.0

In an editorial published in the summer 2007 issue of the *Journal of Health Information Management*, the highly respected American healthcare CIO, Dr. John Glaser, of the Partners HealthCare System in Boston, argues that the country's strategy of creating clinical data exchanges is about to undergo a difficult shift from what he refers to as RHIO 1.0 to RHIO 2.0. He cogently argues that the current vision as described above – which has been actively pursued for the last three years – is flawed.

According to Glaser, many communities are unable to come together in an effective, collaborative way due to intense regional competition, disinterest by key stakeholders and overly fragmented or large, local healthcare markets. Communities also often lack sufficient social capital or ability – the essential building blocks for the creation of an RHIO; they may have never worked together and as a result they have not forged the necessary effective working relationships or trust. Even when that social capital exists, those who form an RHIO must overcome a series of technical and non-technical challenges. Issues such as patient identification techniques, security, governance and privacy are formidable barriers, and many communities are struggling to overcome them. The creation of a clinical data exchange requires capital, at times significant capital, and means to support the financial requirements of ongoing operations.

These demands can prove difficult for providers who face thin operating margins and purchasers of care who are very anxious about the persistent rise in healthcare costs. While the ability of a care provider to see a composite clinical picture of a patient has appeal, its ability to improve the operational and clinical performance of a participating organization or reduce its costs is not clear. In effect, Glaser argues that RHIO 1.0 is seen as being created by hundreds of community collaborations; collaborations that may not happen or are hindered by the political demands of collaboration or cannot identify the business case that would lead participants to invest in the exchange. Of all of these challenges, the financial sustainability challenge appears to be the most significant.

Glaser is of the opinion that the majority of the clinical data exchange in what he calls RHIO 2.0 will be the result of targeted initiatives undertaken by organizations that have very specific business goals. These organizations understand that information technology and connectivity can advance their own corporate strategies. He cites as an example, the creation

of RxHub (<http://www.rxhub.net/>) and Sure-Scripts (<http://www.surescripts.com/>), which have both made considerable progress in putting together medication-centric clinical data exchanges. Corporate pharmacy benefits managers (PBM) see the electronic exchange of medication-centric transactions as a way to managing medication ordering based on a formulary and reducing medication errors through the transmission of medication history information.

According to Glaser, RHIO 2.0 will not be an orderly vision of community-based exchanges that are united by a NHIN. Rather RHIO 2.0 may take the form of chaotic convergence of diverse and often disconnected connectivity interests. Moreover, the result is the natural consequence of a national healthcare IT strategy that relies primarily on free market forces to create interoperable electronic health records. In a free market based approach, providers will take steps that they see as necessary to improve their care quality and strengthen their margins through increases in patient volume. Purchasers will take steps to improve the service they provide to their subscribers and reduce the costs and increase the quality of care. Pharmacies, laboratories and radiology centers will make investments necessary to improve the services that they deliver. And each of these organizations, taking perfectly rational managerial steps, may inevitably realize that comprehensive community connectivity may not be necessary.

Glaser closes by warning that for the next several years, the United States should be prepared for the demise of many RHIOs and the dominance of free market-based exchanges. The forces are not sufficiently powerful at this time to shape a different outcome. While disconcerting, this process is the natural result of the country learning about how best to approach clinical data exchanges. The chaos may be a necessary learning experience – in the same way that the fallout from the dot com era was a necessary learning experience about which business models would be viable in Web-enabled world.

Conclusion

Though they include the word “Regional” American RHIOs should not be mistaken for Canadian Regional Health Authorities. RHIOs have no power whatsoever to dictate their “members” IT environments – they are mostly just trying to get the various healthcare organizations in an area to voluntarily share data. Though we tend to complain about them, there is much to be said in favour of the health system governance models in most of our Canadian provinces.

What lessons can we learn from the American RHIO experience? We could do worse than taking a look at the Glaser observations and building on them. Are we fortunate that we have “communities that have worked together and as a result have forged the necessary effective working relationships and trust”? Are we making progress on issues such as patient identification

techniques, security, governance and privacy – the formidable barriers that many American communities are struggling to overcome? Are we further along in tackling these issues than we were three years ago? If the answer is yes, then maybe it is the Americans who can learn from us.

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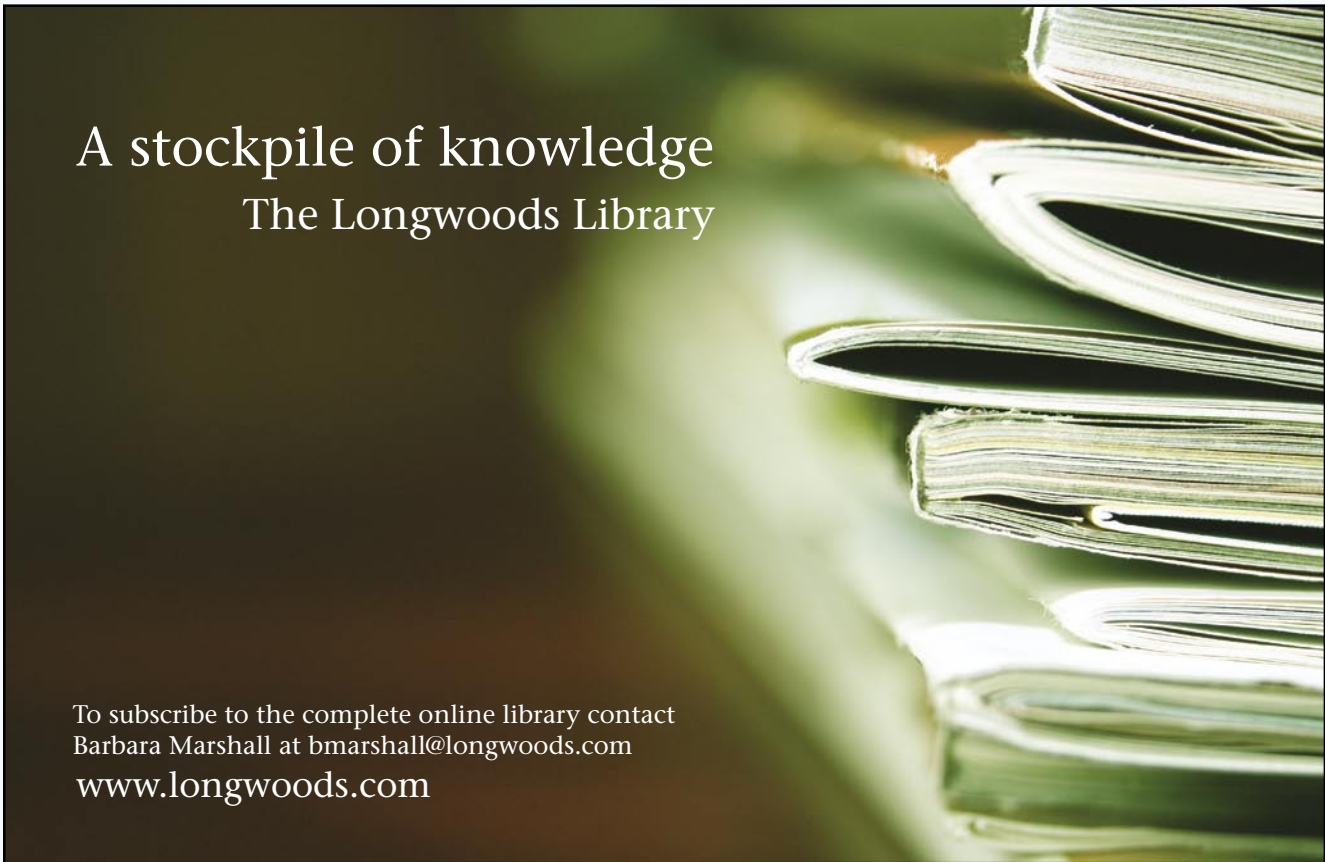
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About the Author

Denis Protti is a professor in the School of Health Information Science, University of Victoria, Victoria, British Columbia, and a visiting professor at City University London.



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Commentary

Why RHIOs Aren't Working: Views from an American Who Can See White Rock, British Columbia, from His Backyard

David E. Garets, FHIMSS

The problems with RHIOs (often referred to as health information exchanges) in the United States have as much to do with the structure of the American health “system” as they do with non-existent business models for funding them after the grant runs out and lack of interoperability standards.

Misaligned Incentives

Our “system” is “distinguished” by an incredible lack of aligned incentives.

- Insurance companies want to keep their insured consumers from engaging in expensive procedures or showing up in expensive venues (emergency departments) and have a reputation for looking for creative ways to not pay for medical services.
- Hospitals think they're the centre of the medical universe and make their money getting most of the sick people and providing as many services for them as are reimbursable by the tight-fisted insurers.
- Most American physicians are independent business people trying to maximize their incomes and attempting to gain leverage from hospital competition in their communities.
- Pharmaceutical companies, for the most part publicly held manufacturing firms, are intent on maximizing their profits and have figured out how to be successful – spend billions of dollars lobbying the US Congress to keep price controls and imported drugs out of the country while marketing directly to consumers.
- US residents, 47 million of whom are uninsured (approximately 16% of the population), are left to fend for themselves with competing doctors, hospitals, pharmaceutical companies eager to have them “ask your doctor whether whatever drug we're pushing today is right for you.” In the United States, the costs for this madness are escalating far faster than inflation and presently comprise at least 15% of the US gross domestic product, a far higher percentage than in any other developed country, with poorer outcomes.
- And finally, employers, who fund a large percentage of the healthcare costs for employed Americans and their families, are furious at the increasingly large bite employee and retiree healthcare costs are taking out of their profits, making it increasingly difficult for many of them to be globally

competitive. They're trying to get a handle on containing those costs. In large part, they attempt to manage this by shifting more of the costs to their employees.

I don't mean to be cynical, but RHIOs are the least of our worries!

Let Me Count the Hurdles

Let's look at what RHIOs are trying to do with that "system" in mind. As Professor Protti writes, they're trying to "facilitate the secure exchange of healthcare information to advance the effective and efficient delivery of healthcare for individuals and communities." A noble goal, but what's in the way? Let me count the hurdles:

1. About half the hospitals in the United States are located in communities where there are one or more competing hospitals in town. They mostly don't like each other and don't trust each other. I've had CEOs of competing hospitals tell me that they've spent millions of dollars building their electronic medical record systems (EMRs), and not for the purpose of sharing data with their competitors.
2. Private practice physicians want the best for their patients, but not to the extent of implementing ambulatory medical records systems to make the care they give more efficient, effective and safer. The overall penetration of those systems in the United States is below 20% in most of the studies of ambulatory EMR adoption. So that means that somewhere north of 80% of physicians in the United States still have paper clinical records (almost all of them have practice management systems to get their claims and bills out). Participating in a health information exchange or RHIO where the expectation is that the clinical data will be in digital form is a non-starter for many physicians, especially those in individual or small group practices.
3. The entities that benefit from the information a RHIO would provide aren't always the ones that are expected to pay for it, as Protti points out.
4. The lack of interoperability standards and the unwillingness of our legislators to mandate them cause problems for consumers. First, what comprises a personal health record (PHR)? Is it just laboratory test results and some demographic data? Or is it the Continuity of Care Document? Does the consumer have to key most of that information into the web-based and/or employer-provided PHR? For the majority of people who have PHRs, including me, the answer is yes.

Second, because many of the systems in American health-care organizations (HCOs) are proprietary and there's no controlled medical vocabulary standard in the country, the data coming out of one HCO's systems won't be easily understood by an RHIO's federated or centralized databases.

Progress is being made, but it's slow. The losers? Consumers/patients.

The information exchanges that will succeed are the ones that have their incentives aligned. One reason that Indiana's initiative works, and the ones from Tennessee and Louisiana show promise, is because they're providing services to not just cities, but in large measure to rural portions of their states. That's one source of the "supply" of patients needing specialized cancer treatment, for example, provided by larger urban and academic medical centers. They're not so much trying to hook together competing HCOs as they are facilitating supply chains that align limited services with people who need those services, a pragmatic solution.

The other type of information exchange that will be successful is the model proven by Inland Northwest Health Services in Spokane, Washington. In my opinion, they're not a RHIO, but rather a services provider, delivering healthcare IT services among others. They run a regional MEDITECH data centre more efficiently than the independent hospitals that are their customers could possibly manage on their own. They're an outsourcer to hospitals, and because they specialize in one hospital information system and have the ability to interface and integrate other existing applications owned by their customers for community access, they are able to facilitate the exchange of data between their hospital and physician office customers *who wish to exchange data*.

RHIOs and health information exchanges must focus on collecting and sharing minimal data sets that solve real health-care delivery issues quickly and effectively. Then these can be incrementally expanded as successes are achieved. Most are trying to do too much too soon, exacerbating the mistrust among the stakeholders.

Be Thankful!

Be thankful you have a healthcare system as rational as it is. Your system of regional health authorities and a centralized, national funding source for innovation in healthcare IT (Canada Health Infoway) makes eminent sense. I think it's the model for other nations globally. Now if the United States would just get closer to the way you do it ...

About the Author

David E. Garets, FHIMSS, is the president/CEO of HIMSS Analytics



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