

RHIO Nation

Community hospitals and small or solo physician practices are among the many players who need to prepare for the future world of electronic data sharing.

By Robin Blair, Editor

For an entity that won't exist for another five years at least, the national health information network (NHIN) and its data-sharing building blocks, RHIOs (regional health information organizations), have garnered humongous attention. Type "RHIOs" and one of a dozen terms—Brailer, interoperability, EHRs, healthcare, Leavitt—into a search engine, and hundreds of articles, speeches, blogs, PDFs and public meeting records spill forth.

But getting a handle on real RHIO progress is as elusive as the citations are numerous. That's because there are more than 100, more than 150 and more than 300 RHIOs in existence. Business models are founded on centralized repositories of patient information and decentralized databases owned by RHIO member organizations. RHIOs emanate from single organizations, multiple membership healthcare organizations (HCOs), community origins, individual practice associations (IPAs), state-level mandates and multistate collaboratives. "Herding cats" is a phrase that comes to mind.

A few underlying tenets are easy to agree on: 1) Everyone from President Bush on down supports the idea of an electronic health record (EHR) for every patient, in a nationwide healthcare machine where clinical systems talk to each other and share patient data at the point of care; 2) interoperability requires standards—nationally accepted and agreed upon standards; 3) EHRs must be certified. Providers who invest in EHRs must gain a specific set of functionalities with which they can participate in data exchange, but also operate an efficient, profitable medical practice. So much for NHIN-101.

Beyond Profiling

Beyond that, opinions about critical success factors are as voluminous as the RHIO-related published articles and PowerPoint presentations that litter the Internet. Most of those are profiles of local or regional data-sharing endeavors, attempting to capture in four or five paragraphs what various stakeholders describe as their own RHIOs. Harder to capture is a delineation of real issues that underlie the progress essential to make before the NHIN is constructed, before every patient is supported by an EHR and before hundreds of RHIOs are allowed to interoperate.



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—Tom Lee, M.D.

Epocrates (and private practitioner)



Money is one issue. How much will the NHIN cost and who will pay? Since estimates hover in the billions, another issue is whether the money is a deferment of funds that would have been spent on healthcare services, or does it represent additional healthcare spending?

EHR usability is an issue. Will physicians embrace an EHR, love it, rely on it and use it to improve point-of-care patient care, or go along to get along?

Replication and public domain is another issue. Will it play in a two-physician Peoria practice when the prototype was built for a 65-doctor clinic in Boston?

The granddaddy issue of them all is patients—their data, their privacy, their consent, their understanding of healthcare issues and, most importantly, their involvement. There is not a person involved in RHIO rhetoric or NHIN building who doesn't think it all starts with and centers on patients. Yet, there are many who say patients' rights are about to get steamrolled by NHIN fever.

Definitions and Debates

W. Holt Anderson is executive director of the North Carolina Healthcare Information and Communications Alliance Inc., an organization that, admittedly, is not a RHIO but is a mover and shaker in the advancement of healthcare IT. Anderson has publicly challenged the proliferation of people and organizations describing themselves as a RHIO. "If being able to attach that term helps them to mobilize in their community, fine. At what stage does an organization become a RHIO? I look for multiple, competing enterprises that agree to collaborate, to build connectivity to move health information among themselves, for the purpose of serving patients. These institutions are separate entities that share agreements and policies; these shared agreements and policies will allow them to get clinical information to the point of care."

Anderson commends the visibility for the NHIN and data-sharing RHIOs generated by President Bush, the Department of Health and Human Services (HHS) Secretary Mike Leavitt and Dr. David Brailer, National Coordinator for Health Information Technology. "It's all good," he says of the banner-carrying and speech-making that has landed the NHIN/RHIO vision smack in the public eye via mainstream press. "We need to credit these officials and agencies for being willing to start by looking at the barriers, by looking at business rules within a number of states and extracting from those what the barriers are. Their next investment takes it up a notch to examine the commonalities of these barriers that inhibit the purposeful exchange of information, and then up a notch more to analyze and recommend what can be done to reduce or eliminate barriers."

Nevertheless, he says, bona fide implementation will be a challenge. The healthcare sector has "grown in up pockets around areas of focus and expertise. Healthcare organizations have built what works best for them in their own environments. Now we are saying, 'In order to share information about individuals so we can take better care of them, we must find ways to move information from those pockets into a capability of providing information to clinicians.'" That, he says, is a huge step that will require collaboration and business agreement from several critical audiences.

Patients are one of Anderson's top concerns. "Put the patient at the center of the equation," he says. "The patient must always be the central focus." Anderson hopes the consumer-directed health movement will catch on fire soon and that consumers will self-actualize as decision-makers. "Consumers will begin to push on community health providers and say, 'I'm going to move my business to where I can be sure the information is there when it's needed.'" They exert this influence in other sectors, he says, and healthcare is probably next.

Models: Centralized or Decentralized Data

Where the patient data resides is a RHIO development issue. Make no mistake: Data sharing among hospitals, clinics and physician practices that Anderson describes as "competing" organizations will require formal and legal partnership agreements.

Anderson describes three RHIO models that can cover a lot of the horizon. The co-op model fits mainly small hospitals and rural facilities that lack substantial technology resources and have a good reason to collaborate. HCOs in a co-op model might share both technology overhead and human resources, and might choose a centralized database or shared utility approach to house data and make it available to providers.

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The federated model works for large and independent HCOs coming together as a RHIO. The federated model's decentralized approach to data maintenance would mean that data resides where it was created, in individual facilities, and is shared when necessary by authorized access and according to formalized business agreements, probably to include peer-to-peer requests. HCOs in a federated model would likely develop a system of locating or indexing patient data within the enterprise, and might share an electronic master patient index. The hybrid or combination model would reflect a region with both co-op and federated organizations. Large intra- and interstate RHIOs would likely be hybrid models.

Fed Money: Credit Where It Is Due

Last fall, researchers from Harvard University and Brigham and Women's Hospital made healthcare IT history by publishing in the *Annals of Internal Medicine* a segment of their research into the projected costs of an NHIN. They estimated a five-year cost of \$156 billion capital expenditure with operating costs of \$48 billion annually that included acquisition of software and hardware, implementation and adoption costs plus annual maintenance. Researchers used a hypothetical system model similar to the Santa Barbara County Data Exchange, but on a national scale, to arrive at a price tag for interoperability.



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Vanderbilt Center for Better Health

Researchers and reviewers alike rapidly pointed out that the \$156 billion price tag reflected only about 2 percent of projected healthcare spending during that time period. Lead author Dr. Rainu Kaushal publicly described the cost projection as "actually moderate compared to overall health care expenditures, suggesting that the money is out there, but it may be a matter of prioritizing here it goes."

To its credit, the federal government initially has made wise public investments in the right directions to launch NHIN efforts. Last October, HHS awarded \$17.5 million in three contracts. The first was to

support harmonization of data standards, particularly for EHRs, essential for regional and nationwide health data exchange, with a \$3.3 million award to the American National Standards Institute to convene the Health Information Technology Standards Panel. Another \$2.7 million went to the Certification Commission for Health Information Technology for EHR certification compliance, to develop criteria and evaluate processes that can apply to the more than 200 EHR-related products on the market. RTI International, a nonprofit entity that will oversee the Health Information Security and Privacy Collaboration (HISPC), received more than \$11 million in security and privacy funds; HISPC will work with 40 states to assess state laws and typical HCO business policies that can pose barriers to data sharing.

One month later, HHS awarded another \$18.6 million to four consortia, to begin building prototypes for the NHIN architecture. Each consortia will build a standards-based network prototype to reflect patient identification locator services, user authentication, access control and the feasibility of large-scale deployment. Included in the recipient rosters are already well known and successful data-sharing collaboratives such as the Indiana Health Information Exchange, MA-SHARE, HealthBridge and CareSpark, and respected vendors such as CSC, Accenture, Apelon, Cisco, Axolotl, First Consulting Group, IBM and Sun Microsystems. All four consortia will report results and findings to the American Health Information Community, an advisory group chaired by HHS Secretary Mike Leavitt.

It's a great start, with money well invested in the right directions. Now, where is the remaining \$155.9 billion going to come from?

Usability for Physicians

If we build it, the question isn't whether or not doctors will come. They will come, because their Medicare, Medicaid and insurance payments will depend on it. The question is whether or not we build a system that appeals to physicians enough to capture their utilization, loyalty and reliance on it as a vehicle for improved patient care—and subsequently, whether patient care actually improves.

Tom Lee, M.D., is an internist in private practice in a paperless medical office, vice president of product management at Epocrates and a physician who builds software systems for physicians. In his online August 2005 iHealthbeat article "The Evolution of RHIO Economics," Lee delineates six functionalities that are critical to achieving the NHIN vision from a physician perspective: 1) electronic health records for patients; 2) computerized physician order entry; 3) electronic viewing of patients' test results; 4) e-prescribing; 5) electronic eligibility verification and claims submission; 6) secure electronic communication with patients.

Lee is quick to distinguish between EHRs that offer adequate clinical functionality that suffices for all doctors and software that physicians like, use and depend on. "What I want to have available as a clinician is a different issue from what is needed to build an interoperable nation." Most EHRs, he says, are still not designed with physician intent; they are designed to support the business of the medical practice, and to a lesser extent to support reporting functions and public health requirements. "People don't really know what physicians want. Physicians are so trapped in practice and in delivering medical care to patients, it's hard to carve out the time to elicit their responses, and some don't know." Even then, he cautions, it's important not to "overinterpret physicians' opinions," and to not "overweight" either the system's needs or physicians' needs in building that interoperable nation.

Certification of EHRs will help to a point, in the context of supporting clinical data standards and interoperability, but Lee warns of their downside. Certification also can act "as a barrier to truly innovative products, because it puts constraints on innovation."

Even with robust, albeit plain vanilla, EHRs on the horizon, physician adoption isn't guaranteed, and Lee is lukewarm to the idea of incentives. "Docs aren't motivated by money," he says, "but by the ability to care for patients and do good for society. It's one thing to incent adoption of things that are helpful. It's another to try to incent adoption of things physicians' don't want to adopt. Physicians rapidly adopt what is perceived as helpful in treating patients effectively and will maximize the use of their time."

Planning for Inclusion of Solo Practices

Lee heartily credits Dr. David Brailer for his prominent role in foisting critical healthcare issues to the public fore. Brailer, he says, "is developing a roadmap at a high level, and activating both public and private sectors for building an interoperable world." But Lee also is "concerned with the transmission of vision and dollars into reality and implementation. I'm not convinced we have the right organizations, levels of sophistication, and understanding of what clinicians really need. At the end of the day, it's going to be the people on the ground who are building it, wiring it and implementing it."

His concern extends to the multitude of solo and small medical practices and community hospitals that occupy the healthcare landscape. Invariably, those are the same organizations with limited resources to acquire hardware and software. Organizations that now share data in early RHIO demo projects are large organizations with "the capabilities to be doing it now. But, obviously, they are limited because they are large organizations, and large organizations have [typical large organization] issues to cope with, like bureaucracy and policy." Lee cautions that smaller organizations lacking resources, the right structure and possibly the necessary skill sets also need to be equitably planned for as the NHIN vision evolves.

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—Don Mon
American Health Information
Management Association



So, what will work for individual physicians as well as those now constructing an interoperable vision? Lee says the right recipe is a blend of ingredients. It is certified EHRs that still reflect enough innovation and flexibility to earn physician loyalty. It is leadership by large organizations with resources aplenty to engage in data sharing, but probably future subsidies so smaller organizations can participate, too. It is interaction between those who are prominent on Brailer's high-level roadmap with people on the ground doing the building and wiring. Therein are a lot of channels to cross.

Who Ya Gonna' Call? HIM

After physicians, few healthcare professionals will be as touched by the impact of the NHIN and RHIOs as much as health information management (HIM) professionals. But, a groundswell of attention toward HIM professionals' involvement has not yet made the front page.

Among many roles they play, HIM professionals are the maintainers of healthcare organizations' legal medical records. They also are likely to be the cadre of experts called upon to educate patients about the rigors and requirements of professional data exchange, and to educate other HCO staff about access, authorization, security, release of information, privacy and patients' rights.

"Traditionally, HIM professionals haven't been at the executive table," says Don Mon, vice president, practice leadership, of the American Health Information Management Association (AHIMA), but the table is growing. He says AHIMA members are involved in most RHIO initiatives now, serving on standards panels and helping to develop prototypes. But, "there won't be any information exchange if

we don't have critical mass of EHRs," he says. Certification of EHRs is essential to reduce the risk of providers purchasing products that don't interoperate or provide the functionalities they need to treat patients, he explains.

Future roles for HIM professionals can only multiply, as issues of release of information, who owns the data, access to data and patient consent are more sharply debated. "In our view," says Mon, "there is a distinction between where the data resides and release of information, a distinction between owning health information and owning data. Patients 'own' their own health information," while the data collected and assembled into a legal electronic record would be owned by the HCO. "The individual patient, who still thinks in terms of paper files, may not be aware that the legal record, for disclosure purposes, means the organization must preserve the data in the way it was presented to the clinician."

Mon says to also look for HIM professionals as organizational liaisons to the vendor community, helping to represent at a granular level the software HCOs need to have developed and, generally, to be the representatives of stakeholder groups to other stakeholder groups.

Patients: The Center of the Universe

"It's about power," says Mark Frisse, M.D., Accenture Professor of Biomedical Informatics at Vanderbilt Center for Better Health, Nashville, and a shift of power from those who provide care to those who receive care. "Until the public is more informed and more insistent about the quality of its healthcare, things won't change."

Like Anderson, Frisse is at the front of a long line of healthcare experts who place patients at the center of the NHIN and RHIO equations. He's clear—patients are why we are building the national machinery. But he also is realistic and quick to challenge the authenticity of public assumptions. "Let's look at the facts. We know the healthcare system doesn't meet the needs of many, and that the current approach is not sustainable. We know every dollar is spent somewhere, and that large amounts are spent. We know there aren't enough dollars spent on patient care." So we must question, he says, whether the transfer of dollars spent on patient care to the means to reach the objective—better patient care—is a correct approach. "Find another industry that spends money in this way," he says.

At the same time, he admits, "How can we not afford to do this?" Frisse doesn't support challengers who have questioned the vast amounts of funding necessary for an NHIN, and whether the nation wouldn't be better off conservatively building one or two successful state-level RHIO demonstration projects. "Every state is doing great things," in its own way, he says. "Everyone is teaching us a different part of the answer. As a nation, we have never made great decisions by relegating responsibility to one particular state."

Friss is especially encouraged by two trends emanating from critical audiences. One is IPA-centered communication and exchange networks, such as the Taconic Health Information Network and Community (see box, page 61), in which hundreds of providers can electronically communicate, request data and exchange information. He agrees with Lee: Inclusion of small practices in large electronic networks that "enable care through information technology" is the last mile, and it needs to be planned for and accommodated. He counts on IPA-based networks to pave the way.

A second trend is increased consumer involvement in personal health records and electronic management of personal health and financial data. Employers that furnish employees with electronic management capability, either as a company benefit or through an employer-sponsored health plan, are moving consumers toward empowerment and, hopefully, activated decision-making. Similarly, software

vendors are venturing into this market segment with products geared to electronic health and health administration management for consumers. It's like Quicken for allergies and HSAs.

Patients' Rights: The Granddaddy

Last year, John Smaling of Vitalize Consulting authored a daring *HMT* article on the nontech integration requirements of building RHIOs, pointing out that the people, policy and political issues are harder to overcome than IT obstacles. In researching that article, Smaling spoke with a CIO of a healthcare organization publicly heralded for advanced adoption of IT about how patients will choose to opt-in or opt-out, once data sharing is a reality. The response? It is a nonissue. Most likely, the CIO said, patients will be presumed to opt-in. Opting out, i.e., denying consent to have their medical data shared, may not be an option. "Seek patient status elsewhere" could be the retort.

Deborah C. Peel, M.D., might take issue with that. Peel is a practicing psychiatrist and founder and chairman of the Patient Privacy Rights Foundation (PPRF). She is on fire about patients' rights and privacy. "Consumers should be asking for restoration of all rights they had until April 2003. Every patient should be saying: 'I want to decide who can see and use my medical records; I don't want my records or my family's records shared with any employer; I should never have to choose between privacy and healthcare.'"

As a psychiatrist, Peel says her specialty, more than most, has the need to see millions of electronic patient records in a database, deidentified, "so we could conduct the meaningful, longitudinal research necessary to help us learn how to manage mental health cases over a decade, not just the first two weeks of treatment." Yet she remains fiercely dedicated to phrases like "in the aggregate" and "deidentified," and cautious about anything that borders on blanket patient consent.

She fears the possibility that employers, in possession of medical data, could use information to discriminate against employees or avoid hiring certain employees, and says the risks are great with unbridled access to data. "Nobody is their diagnosis. Diagnosis doesn't predict who can work and who can't. It doesn't predict who will be hard-working, tax-paying and productive. When information gets into the wrong hands, it can be used for wrongful purposes."

Yet, according to Peel, the PPRF is pro-technology because technology can foster privacy and safeguard patients' rights. It is easy for software developers to build patient consent into applications. To her, consent is a data field; it can be added or eliminated to physician practice management and EHR software.

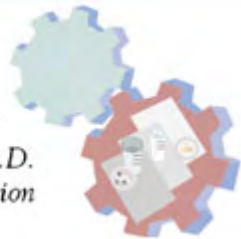
Opt-in, Opt-out or No Choice

Peel is not alone in her concern. In published testimony before the National Committee on Vital and Health Statistics Subcommittee on Privacy and Confidentiality last August, Pam Dixon, executive director of the World Privacy Forum, offered several examples of identify theft and subsequent fraud committed through illegitimate access to and use of individuals' medical records. In some cases, perpetrators actually altered medical data of the individuals whose records they stole.

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between privacy and healthcare.'"

—Deborah C. Peel, M.D.

Patient Privacy Rights Foundation



Dixon also publicly questioned which patients, if any, get to opt-out of automatic data-sharing by their providers. "Allowing patients to opt-out of having their records enter a larger network will be an important right to confer going forward," her testimony offered. "If ... only members of Congress, public figures and law enforcement

officials are allowed to opt-out of the NHIN ... how will this be explained to the public, and when?" In continuing to caution about blanket consent, Dixon said, "Concerns about consent in EHRs or networks involving EHRs is not an academic point. Patient consent in electronic environments is already an issue, however it is being ignored in practice."

Following the 2005 devastation of Hurricane Katrina, dozens of pundits painted the picture of an unconscious patient being wheeled into a hospital ER and used the image to substantiate the need for EHRs for all patients. It's an unrealistic image, says Peel, who herself has run an emergency room. "Hardly anyone ever comes into the ER completely unconscious with no one to speak for them." Even then, she says, a battery of diagnostic tests exists to determine the first step of treatment. She says a physician who would rely solely on an EHR without simultaneously conducting the necessary diagnostics would probably lose the patient.

Interoperable World Without End

The world of federal agencies, Congress, political appointments, state legislatures, million-dollar grants, prototype demonstration projects and lunch with the President is a world where it's hard to keep one's head out of the clouds. The buzzwords alone can be ethereally mesmerizing.

RHIO nation will be built and wired by the people on the ground, or it will fail. The picture 10 years hence is hard to predict, but no one summarizes it with a better combination of zeal and temperance than Dr. Tom Lee. "Momentum will continue, large systems will lead the charge, and we will have adequate systems that are semi-interoperable. Whether they improve care and systems of care, I'm more skeptical there. My hope is that someone has the vision to build something truly disruptive. Maybe it will be me."

Maybe it will. Stay tuned.

Do-It-Yourself RHIO Research

Taconic Health Information Network and Community. Read the robust story of THINC, the Taconic Health Information Network and Community. Author Dianne Koval, R.H.I.A., provides a richly detailed recap of an operating RHIO in "Real-World RHIO: A Regional Health Information Organization Blazes a Trail in Upstate New York." She describes the leadership role of the Taconic IPA, an organization representing about 500 practices and 2,300 physicians, in shaping the building of the Internet-based infrastructure, physician adoption and successful data exchange including standards adoption, payer support and physician adoption. The article is housed online in the AHIMA library.

www.rsleads.com/602ht-205

MedVirginia is the state of Virginia's RHIO, founded in 2001, and the owner of MedVirginia Solution, a health information exchange that assimilates hospital, pharmacy and lab data into a single electronic

chart, available to serve clinicians via a secure Web portal. With funding from Bon Secours Richmond Health System, MedVirginia plans to host Wellogic's EMR software as a cost-effective option for RHIO participants. The RHIO already includes a large physician practice that uses an EMR and wants to share data with referring physicians. www.rsleads.com/602ht-206

The Patient Privacy Rights Foundation, founded by Dr. Deborah C. Peel, offers a wealth of information about pending, passed and prospective legislation that affects the rights of patients and consumers to medical-data privacy. Click on the "Press Stories" link for a plethora of media coverage of privacy issues from ComputerWorld, The New York Times, The Washington Post, MSNBC.com and The Boston Globe. www.rsleads.com/602ht-207

World Privacy Forum. Pam Dixon, executive director of the World Privacy Forum, gave testimony before the National Committee on Vital and Health Statistics Subcommittee on Privacy and Confidentiality in August 2005. She eloquently addressed the issues of patient choice, privacy and security in a digitized world of electronic health records and the NHIN, focusing on risks that can be mitigated now, in the early development stages. Dixon included examples of identity theft stemming from invasion of individual medical records and addressed difficult issues of patients opting-in or opting-out of electronic data sharing among their providers. www.rsleads.com/602ht-208

Indiana Health Information Exchange, known industrywide as IHIE, is a two-year-old functioning RHIO, originally founded by a group of 13 organizations representing hospitals, public health organizations, researchers and economic development groups. The organization's mission is to connect Indiana HCOs, first in central Indiana and eventually throughout the state, via an infrastructure that supports electronic communication, data sharing and information exchange. www.rsleads.com/602ht-209

Massachusetts Health Data Consortium, founded in 1978, is an elder in the realm of RHIOs. The organization has a fully developed board, mission statement, services, membership rosters and Web content—including MA-SHARE, a collaborative effort aimed at statewide data sharing for improved clinical decision making. Its Web site is a portal to a wealth of RHIO-related information, including MA-SHARE projects focused on EMRs, community MPIs, emergency department data exchange and electronic patient-centric communications. www.rsleads.com/602ht-210

"Accelerating Transformation Through Health Information Technology" is a 54-page white paper and report on recommendations resulting from the October 2005 Center for Health Transformation (CHT) Connectivity Conference, published by the CHT and IDX. The report includes recommendations aimed at immediate and future funding of IT initiatives, federal legislation and regulatory structures to protect health information and adoption of service-oriented architecture by vendors. www.rsleads.com/602ht-211

AHIMA. Read Kevin Heubusch's "Interoperability: What It Means, Why It Matters" in the AHIMA library. Heubusch says it succinctly for HIM professionals: "In one way or another, every HIM story this year will relate to interoperability." Heubusch covers a lot of ground in a short page count, including the Center for Technology Leadership, HHS and EMR certification—all from an HIM perspective. www.rsleads.com/602ht-212