Re-visiting Innovation in the NYS Health Care System:

A Presentation on Disease Management, New Technologies and Public Policy

Executive Summary

New York Health Products Council Forum

May 19, 2006

Introduction

On May 19, 2006, at the Empire State Plaza, the New York Health Products Council hosted "Re-visiting Innovation in the NYS Health Care System: A Presentation on Disease Management, New Technologies and Public Policy," moderated by John Rugge, M.D., CEO, Hudson Headwaters Health Network and featuring Laura L. Adams, President and CEO, Rhode Island Quality Institute (RIQI).

Dr. Rugge is a family physician and the founder of Hudson Headwaters Health Network, a system of community health centers that serves New York's Eastern Adirondack region. He has also served as a state and federal policy advisor, including previous service as Chair of N.Y. Governor Cuomo's Health Care Advisory Board and current membership in U.S. Secretary Leavitt's Medicaid Commission.

Laura Adams's RIQI is a collaboration of the top leadership of healthcare stakeholders working together to transform the health care system in Rhode Island. The Institute is currently leading and coordinating multiple initiatives to promote the adoption and full use of health information technology and health information exchange throughout Rhode Island. Ms Adams is a faculty member of the Institute for Healthcare Improvement in Boston and was Founder, President and CEO of Decision Support Systems, a New York-based company specializing in Internet-based health care decision support.

In her presentation, "Health Information Technology: A Trojan Horse for Transformation?" Ms Adams emphasized the need for quality improvement in healthcare, and helped to define the role of information technology and Regional Health Information Organizations (RHIOs) in improving the quality, safety and value of health care.

The forum also featured a three-person reaction panel representing business, physicians and consumers: Elliott Shaw, Director of Government Affairs, the Business Council of New York State, Inc., Dr. Kallanna Manjunath, Vice President of Medical Services for Whitney M. Young Jr. Health Services, and Dennis deLeon, President of the Latino Commission on AIDS.

The need to improve the delivery of healthcare in the 21st Century.

The United States ranked 36th in a 2000 World Health Organization study the functioning of the health care systems of 191 industrialized nations. The U.S ranked just behind Costa Rica and just ahead of Slovenia.

The root cause of this rank is multifold – care is fragmented, the US has millions of uninsured, evidence-based care is not reliably delivered, and so forth. On the delivery side, the emphasis is on specialization. But treating one isolated medical condition is impractical, because each patient presents a combination of factors. Sixty-six percent of all Medicare expenditures are spent on the care of people with five or more major medical conditions.

Neither good outcomes nor cost effectiveness will result from sending patients to five or more specialists and trying to coordinate and manage their care, unless coordination and on going management of patients with multiple health conditions is rendered through a real-time database.

Fragmentation is one of the reasons that information about performance has been lacking in healthcare reform. We have information that tracks the penny everywhere in healthcare, but we have little information about health outcomes produced that are truly measurable.

What it all comes down to is fragmentation – the Achilles' heel of our healthcare system.

The Problems Driving the Need for Change

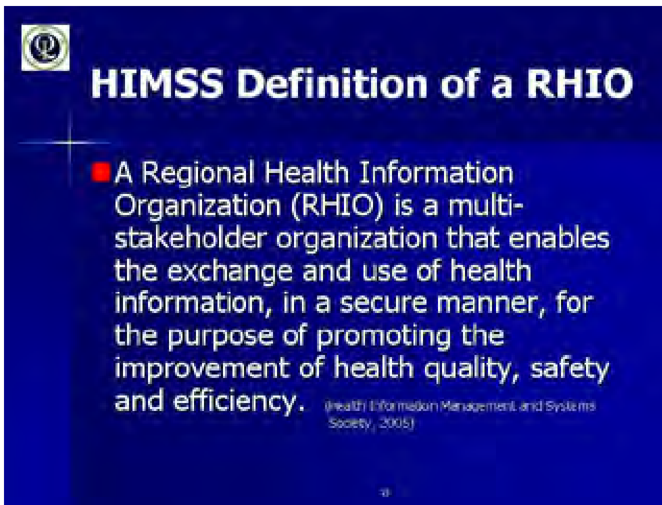
- Cost of care
- Lack of continuity of care
- Patient dissatisfaction
- Slow (or nonexistent) performance feedback loops
- Perverse incentives
- Variation in practice
- Significant quality and safety problems (e.g. WHO 2000 study)*

* *The World Health Report 2000 – Health systems: Improving performance.* Published by the World Health Organization, Geneva, Switzerland. Price: 15 Swiss francs (10.50 Swiss francs in developing countries)
ISBN 92 4 156198 X

How Information Technology, Regional Health Information Organizations and Evidence-Based Medicine can add value and deliver quality improvement to healthcare.

The problems driving the need for change are many. A Regional Health Information Organization (RHIO) may hold promise for addressing a number of the problems of our health care system.

A RHIO is a multi-stake holder organization that enables the exchange and use of health information in a secure manner for the purposes of promoting the improvement of health quality, safety and efficiency.



There is no standard definition of a RHIO beyond the general description. There are more than 150 "RHIOs" in the nation, however anyone may call themselves a RHIO. "RHIO" may range from simply facilitating some electronic prescribing to developing full-scale statewide connectivity, including Electronic Health Records in the ambulatory setting and Personal Health Records in the home.

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The ideal system will allow electronic exchange of healthcare information anytime, at the point of care.

EBM: "the routine availability of information on health care performance at all levels."

Evidence-Based Medicine (EBM)

In a 2003 RAND study, Elizabeth McGlynn and other researchers described EBM as **"the routine availability of information on health care performance at all levels."**

Healthcare Information Technology (HIT)

The RAND report, published in the New England Journal of Medicine, also stated, "Making such information available will require a major overhaul of our current health information systems, with a **focus on automating the entry and retrieval of key data for clinical decision making and for the measurement and reporting of quality."**

Regional Health Information Organizations, (RHIOs) offer something that's been absent from every other reform – everyone is at the table, a collective vision has been set and everyone's behavior is public relative to their actions in service of that vision.

The benefits of health information technology also span a significant range, for example, it will enable a physician to know whether the patient actually picked up the prescription an hour, a day or a week ago. This can help them in managing that person's chronic illness. On the other end of the spectrum, HIT can enable the type of data collection that would allow the ability to assess whether major policy decisions have actually produced the intended result.

HIT can also help to address wide variations in outcomes and unnecessary waste in the system. In a variety of studies, delivery system waste is consistently measured at 30%.

Quality improvement has had a difficult time taking hold in healthcare because the payment and incentives systems are misaligned. Under the current system, the sicker the patients, the more money healthcare professionals earn. When they attempt to improve quality, it can have an adverse effect on revenue because of the design of the payment system. There is enough money to take care of everybody who needs care in the way that we want to ethically treat people. The solution is to start redirecting it – and ferret out that 30% waste.

HIT: Focuses on automating the entry and retrieval of key data for clinical decision making and for the measurement and reporting of quality.

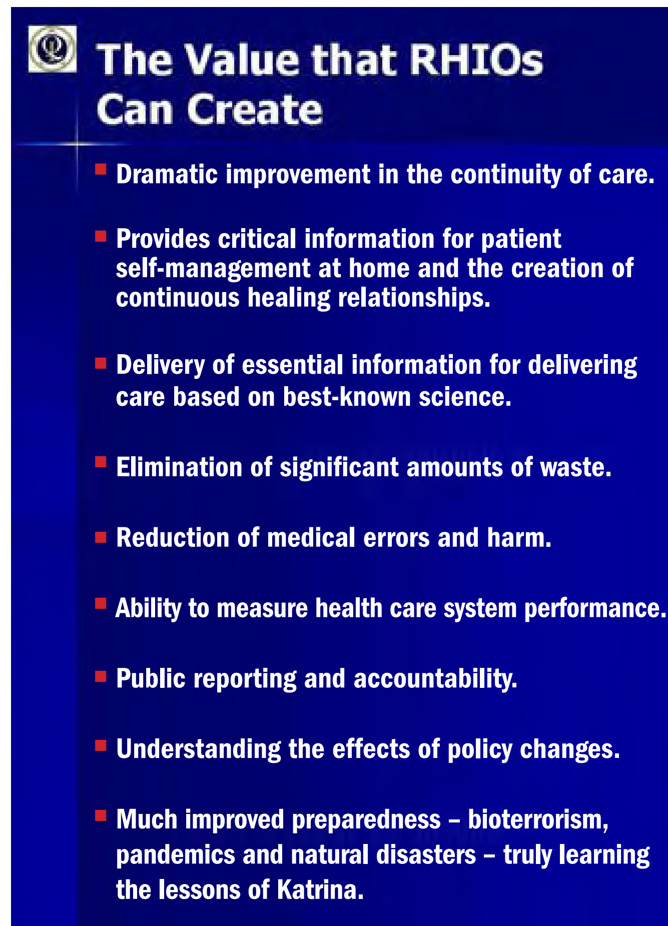
An example of success using EBM.

The nation's success in treating childhood leukemia is one good example of appropriate application of Evidence-Based Medicine. There are nationwide standards for childhood leukemia. The child, once diagnosed, is randomized onto one treatment option or another, and the treatment path is followed. All the outcomes are collected at a national basis; we then begin to understand which arm of those treatments really was the best. It is a real-time, continuous research base. And the remarkable outcome demonstrates our capacity to improve using "real-time science" and having each patient informing the care of the patients that follow.

It was accomplished by having health care professionals follow defined, evidence-based regimens and while using real-time evidence to switch all the children to effective treatment.

The Value of Continuity, Information and Measurement from RHIOs.

The types of challenges that patients with chronic care face today requires "continuous healing relationships" with patients, rather than episodic, fragmented care. Delivering this much needed care in-between visits strengthens relationships as well as produces better outcomes.



When discussing the importance of measurement, Laura Adams gave this example *"In healthcare, we're constantly looking at the price tag and not the overall value. For example, the idea of looking at the price tag of pharmaceuticals without looking at what economies they produce in the marketplace – whether or not those patients don't get hospitalized as much – we don't have good system for measuring the value of that in relationship to the overall system. W. Edwards Deming – who brought Japan's economy back from WWII – demonstrated that point when he was asked how much his thick-soled "engineer shoes" cost. He said, "I don't know. I'm not done wearing them yet." His point was, if he wore them for the next 15 years, they were cheap. If they wore out next week, they were expensive."*

A Promising Demonstration: the Rhode Island Quality Institute. (RIQI)

RIQI is a multi-stakeholder organization that began not as an IT group, but as a healthcare multi-stakeholder group of top-level leaders with a mission to redesign the health care system in the state of RI. As they began work to evaluate possible projects that could be leveraged for significant change, IT was seen as foundation for almost all other critical improvements.

The principles that Guide the RIQI

- Collaboration
- Real improvement in quality, safety and value
- Focus on system improvements that none of us can achieve alone
- Transparency – the "right to know"
- Commitment to a patient/consumer-centric system with an emphasis on patient control, privacy and security
- Senior leaders required– as said to the CEOs and highest-ranking leaders, "You can bring anyone else you want to the meeting, just not as a substitute for yourself."

The institute is funded by participant grants, contributions, contracts and payments for services.

The need for public/private partnership.

One of the major tenets is that this is most likely to succeed if developed as a public/private partnership.

The RIQI board is made up of the senior-most leaders of hospitals and health systems, physician groups, consumers, state government, academia and business. These are people who can change the behavior of their peers. It is important to note that the RIQI has a strong consumer voice, since having consumers and consumer advocates at the table makes it much more likely that any health information exchange initiative will be designed in such a way to earn the trust of the public.

And in the Institute, size or money does not equate to more votes at the Board level – it's one vote per person/organization—a level playing field.

Transparency is also important. The Institute controls no one in RI—it controls no contracts, doesn't regulate anyone, etc. Its strong influence and position in RI comes from a clear and energizing vision of a future for healthcare that is far better than the one that's faced if organizations continue to act alone. RIQI's commitment is to a patient/consumer centric system.

The challenges of privacy and security.

RHIOs present a sliding scale of privacy and security challenges that increase in complexity and sensitivity as the use of the data in the health information exchange is broadened. The challenges will be different, depending on the data sources, types and uses: clinician to clinician patient care and the business of patient care; the collection, processing, analysis and repackaging of identifiable data for one or two organizations; aggregate de-identifiable data for sharing and private use; and individual and aggregate identifiable data sharing.

New consents, new laws and protections will be needed. Cooperation in one area can catalyze conversations and more cooperative behavior in other areas.

Conclusion

To investigate the viability of bringing these new disciplines together, Dr. Rugge concluded the presentation by asking a relevant question of each member of the panel, who collectively represent three stakeholders: consumer, caregiver, and business. Their responses led to a lively discussion of the importance of improving the delivery of healthcare through the use of Information Technology.

Will the Consumer trust it?

Dennis deLeon, the consumer advocate on the reaction panel called upon his own experiences with government and the health care industry to offer some relevant insights. He pointed out examples of consumer mistrust of flawed systems, which are under tight government control, in which only costs are taken into account, and actual health outcomes from medications in real time aren't considered. He believes the NYS Preferred Drug List (PDL) program is focused exclusively on cost issues.

On the positive side, he noted that consumer activists are included in decisions about HIV treatment, including the NYS Department of Health Aids Drug Assistance Program, an accommodation that has earned the trust of the AIDS community.

DeLeon agreed with Laura Adams that there cannot be a system that people will trust and that will change healthcare, unless the consumer's voice is equal at the table. Ms. Adams pointed out that on the RIQI board and Executive Committee is a staunch consumer activist who insures that the organization will really serve the public.

Will the Physician use it?

Dr. Manjunath, the physician on the reaction panel, was very enthusiastic about RHIOs. He reported that he has seen the value of such on a small scale – the power of having the right information. Information will help create the kind of environment wherein patients are in charge of their condition. This responsibility will facilitate a transition to wellness management; Dr. Manjunath defined this concept as being how best we can ensure that a person with illness can maintain a good quality of life for the longest time.

Will Business buy it?

According to Elliott Shaw, business will not only buy it - business will sell it. Many of the solutions to IT are from the business community. IT will be driven not only from the quality side of corporate America but from the marketing and sales side as well. Mr. Shaw also offered an insight into how the business community decides where to invest the money on quality initiatives. There's a 12 or 13-person group called the Community Technology Advisory Assessment Board in Rochester, New York. Within this group, all the stakeholders come together – including a consumer advocate - to talk about Evidence-Based Medicine. The healthcare provider makes a presentation to the group; they begin a dialog and end up with a recommendation. The group has very good conversations around the need and desire for Evidence-Based Medicine.

Everyone at the table agreed Information Technology is coming to healthcare, and that it offers great hope for the improvement of care and the utilization of resources. That agreement signals an important core requirement, however, and that is that in the formation of the approach to this technology, that all factors and all stakeholders play an equal role.

Within this framework, equal partnership among caregivers, consumers, government and business is vital to the successful implementation and utilization of technology.

Equality can build trust; trust can result in the kind of cooperation that will foster the sharing of comprehensive information about outcomes - Evidence-Based Medicine.

Evidence-Based Medicine, allowing the measurement and comparison of each healthcare component will, in turn, lead to greater value, economy and outcomes.

That kind of public/private partnership is beginning to be established in Regional Health Information Organizations, and that is what will give Information Technology its great potential for real reform. There are many obstacles to overcome, but if all members of the community are included in Regional Health Information Organizations, and if the outcomes of Evidence-Based Medicine are shared, there is a chance to bring real reform to healthcare. The risks are many, the process long and difficult, but the potential rewards of wellness management, greater value and access to healthcare are within reach.

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