Special Communication

Consumer-mediated health information exchanges: The 2012 ACMI debate

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ABSTRACT

The American College of Medical Informatics (ACMI) sponsors periodic debates during the American Medical Informatics Fall Symposium to highlight important informatics issues of broad interest. In 2012, a panel debated the following topic: "Resolved: Health Information Exchange Organizations Should Shift Their Principal Focus to Consumer-Mediated Exchange in Order to Facilitate the Rapid Development of Effective, Scalable, and Sustainable Health Information Infrastructure." Those supporting the proposition emphasized the need for consumer-controlled community repositories of electronic health records (health record banks) to address privacy, stakeholder cooperation, scalability, and sustainability. Those opposing the proposition emphasized that the current healthcare environment is so complex that development of consumer control will take time and that even then, consumers may not be able to mediate their information effectively. While privately each discussant recognizes that there are many sides to this complex issue, each followed the debater's tradition of taking an extreme position in order emphasize some of the polarizing aspects in the short time allotted them. In preparing this summary, we sought to convey the substance and spirit of the debate in printed form. Transcripts of the actual debate were edited for clarity, and appropriate supporting citations were added for the further edification of the reader.

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1. Introduction

The American College of Medical Informatics (ACMI)[1] periodically sponsors a debate at the AMIA Annual Symposium that focuses on some informatics topic of national or international import. The debaters are ACMI fellows who take on the task as an educational service to the community and attempt to present balanced discussion that may at times be counter to their personal position on the topic.

This paper is based on a transcript of the session, which has been edited for clarity and to remove the colloquial language that is characteristic of oral presentations.

2. Introductory remarks

The topic of the 2012 debate addresses the level of patient empowerment that is possible and desirable in health information exchanges (HIEs). HIEs have been discussed in the biomedical literature since at least 1957 [1]. In the US, work on HIEs began in earnest in the early 2000s, with the primary focus on patient data exchanges between large healthcare institutions. These initial HIEs were usually provider-oriented regional arrangements, with very little patient involvement. However, the US patient empowerment movement, which began to garner attention in the mid-1970s [2], gained significant influence with the Health Records Act 1990, the Health Insurance Portability and Accountability Act of 1996, and the Data Protection Act of 1998 – all of which addressed the issue of patient access to their own records.

The topic of the 2012 ACMI debate was "Resolved: Health Information Exchange Organizations Should Shift Their Principal Focus to Consumer-Mediated Exchange in Order to Facilitate the Rapid Development of Effective, Scalable, and Sustainable Health Information Infrastructure." The "pro" position was argued by Dr. William Yasnoff, the Managing Partner of National Health Information Infrastructure Advisors, and Dr. Latanya Sweeney, professor of Government and Technology in Residence at Harvard University. The "con" position was argued by Dr. John Halamka, Chief

Information Officer and Dean of Technology, Harvard Medical School, and Dr. Mark Frisse, the Accenture Professor of Biomedical Informatics at Vanderbilt University.

The discussion that follows captures the comments of the 2012 debate and is divided into eight segments of presentation and rebuttal. Additional points are included that were made during a question-and-answer session with the audience after the debate's completion.

3. Statement in support of the proposition

William Yasnoff (WY): The subject of this debate is health information infrastructure, which the 2001 National Committee on Vital and Health Statistics report, *Information for Health*, defines as "a comprehensive knowledge-based system capable of providing information to all who need it to make sound decisions about health." [3]

The goal of the Health Information Infrastructure is the availability of comprehensive electronic patient records when and where needed. The word "comprehensive" is critical because most of the quality improvement and cost savings that we expect from Health Information Infrastructure will not come from converting our current silos of data into digital form, but rather from having more complete information on patients, particularly at the point of care. Accordingly, we need both fully electronic health records (the subject of the HITECH incentives) and a mechanism for aggregating all the records on a given patient in a particular place at a particular time. The HITECH Act provided over $500 million in funding to the states for the aggregation task.

According to the Office of the National Coordinator for Health Information Technology (ONC), HIE organizations are responsible for sharing health information electronically in accordance with nationally recognized standards [4]. When we add the resolution's concept of "consumer-mediated exchange," the result is what ONC refers to as "personally controlled health record platforms." [4]

"Personally controlled" means that the consumer requests that specific health information be exchanged (this may be a standing request) and specifies with whom it is to be exchanged. Also, the consumer may annotate the information, enabling each consumer to enforce his or her own individual privacy requirements. This is consistent with the "download and transmit" requirement in Meaningful Use stage 2.

The resolution's phrase "shift their principal focus" implies, correctly, that consumer-mediated exchange is not the current principal focus. At present, HIEs are generally intended to facilitate information exchange directly or indirectly from one health care provider organization to another, typically without the consumer's knowledge or approval. In some cases, the consumer may opt out or opt in to the entire process but beyond that has little or no control.

Why is this important? Consider the last phrase in the resolution: "to facilitate the rapid development of effective, scalable, and sustainable Health Information Infrastructure."

At present, we are not moving rapidly towards this goal. The PCAST report from December of 2010 said, "HIE efforts through the states will not solve the fundamental need for data to be universally accessed, integrated, and understood while also being protected." [5] A recent survey of 179 HIEs found that none met the authors' definition of "comprehensive," and just 13 met Meaningful Use stage 1 criteria. The authors therefore questioned whether Regional Health Information Organizations (RHIOs) in their current form can be "self-sustaining and effective in helping U.S. physicians and hospitals engage in robust HIE to improve the quality and efficiency of care." [6]

The resolution's use of the word "scalable" means that once implemented, an HIE should be expandable to larger populations, and ultimately the whole country. However, since the HIEs are not currently effective, scaling them would be counterproductive. By "sustainable," the resolution implies that ongoing recurrent revenue should be sufficient to cover operations. The PCAST report states "The lack of a clear business case for communities to sustain HIEs over time remains a daunting challenge." [5] Similarly, the previously cited HIE survey found only 6, or 3.4 percent, of 179 HIEs were self-reported as sustainable; objective audits might find an even lower rate [6].

Our proposed solution is the creation of consumer-controlled community repositories of electronic health records, otherwise known as health record banks (HRBs) [7,8]. This solves the key problems that are currently plaguing HIEs.

Privacy: Patient control allows each person to establish his or her own privacy policy. In this large and diverse country, this is the only privacy policy that every person can agree on.

Stakeholder cooperation: When patients requests their health care data, all stakeholders must provide such data under HIPAA, and they must provide them in electronic form, so the result is comprehensive records. Both privacy and stakeholder cooperation are essential for effectiveness.

Sustainability: Once you have the information together in one place under patient control, multiple business models are possible, operational costs are low and there are many opportunities to create value with the information. For example, you could have a "freemium" business model [9], popular on the Internet, in which there is no cost for basic accounts; revenue comes mostly from optional apps and anonymized reports for researchers and policymakers. Sufficient revenue (shared with the consumer) is generated to provide ongoing permanent providers with subsidies for cloud-based electronic health records (EHRs). Note that in this business model, there is no need to assume or capture any healthcare cost savings.

Practical: Finally, this is practical to implement. Free EHRs can be offered to physicians in exchange for signing up patients for free health record bank accounts. This yields truly comprehensive electronic records through much higher adoption rates and rapid achievement of critical mass of patients, with a reasonable startup cost of $5–8 million and scalability through replication in other communities.

In summary, HIEs today are not on a path to success. By changing their focus to consumer-mediated HRBs, we can rapidly achieve an effective, scalable, and sustainable Health Information Infrastructure that provides comprehensive electronic patient records when and where needed.

4. Rebuttal to Dr. Yasnoff's statement

John Halamka (JH): We all agree that the goal of ONC is to provide coordinated care, to improve population health, to measure public health. However, I will argue against a few of Dr. Yasnoff's assertions.

First, do HRBs really exist? Google Health is gone. Uptake of Microsoft HealthVault is slow and many find it that it does not provide a highly usable experience.

Dr. Yasnoff states that creation of a sustainable, provider-centric HIE is very challenging. However, In December of 2011 the Centers for Medicare and Medicaid Services (CMS) approved funding for a provider-centric HIE. On October 16th of 2012, we went live with a fully sustainable provider-centric exchange connecting 5000 providers in the State of Massachusetts. Each agreed to pay an amount equivalent to the value they would derive from the exchange. Interestingly enough, when we did a sensitivity analysis,