CLINICAL PATH CONSULTING

Health Information Exchange: Enter IoT & Data Science

By Joe Barron, Vice President, Data Sciences

The idea of Regional Health Information Organizations (RHIO), Regional Health Information Exchanges (RHIE) and, generically speaking, Health Information Exchange (HIE) is not a new concept. Acronyms change - new ones are coined and some are no longer in vogue. Nevertheless, the underlying principle is universal; it is the integration and exchange of health information within regional, national, and even international boundaries. This has been a daunting task that even today has not been fully realized. There are many obstacles, including business models, political agendas, monetization opportunities, and, in some instances, use of technology.

Let us take a brief historical look at these concepts. Almost ten years ago, Harvard University (School of Business) published a paper around the 'state' and 'financing' of RHIOs[i]. The focus of this article speaks in business acumen to the age old political, business and philosophical questions of how will organizations pay for HIE and what is its real business benefit. It also speaks to the adoption and success rate of such entities, which in this period of history was painted as dismal.

A few years later in the evolution of HIE development a research study (grant funded) was published in the Journal of the American Medical Informatics Association (AMIA) citing user perspectives on the usability of a RHIE[ii]. The results of the study are not surprising, specifically from a Computer Science perspective. Usability of the access modality, accuracy of information, and inherent robustness (the ability to assimilate new information into the system quickly) were all statistically significant key outcomes of this study.

More recently, a study was conducted around the eHealth initiative and lessons learned in Switzerland[iii]. What is notable about this study is that it speaks very clearly to the fact that HIE development, even in smaller geographical areas, is difficult, politically challenging, and time consuming. Ten years elapsed from the initial government mandate to the first implementation. The major factors cited for the long duration included politics, law and voluntary participation. Technology was not considered an impediment which may be surprising to some.

Reflecting on the above studies (and there are obviously a google more) as variables in the HIE equation, it is not surprising that such an undertaking in this country is staggering. If we leave technological attributes aside for the moment and consider business case, usability, politics, legal issues and participation, it is readily apparent why such initiatives stall and/or are monumentally difficult.

Enter law and politics. In the US, we have the Health Insurance Portability and Accountability Act (HIPAA) enacted in 1996 under the Presidential term of Bill Clinton[iv]. It is also known as the Kassebaum–Kennedy Act or Kennedy–Kassebaum Act. There are two major areas of focus within HIPAA; notably Privacy and Security. While the Act is intended to secure the individual (and population) from healthcare malice, it does have significant tangential ripple effects. Consider medical research for instance. A study published by the University of Wisconsin-Madison almost 10 years after HIPAA was enacted suggests that HIPAA appears to inhibit medical record and database research[v]. If the hypothesis of this research has foundation, then a plausible extrapolation would suggest prominent research studies, conducted by credentialed medical researchers utilizing the plethora of information that an REI could manifest, would be in many respects impeded. During the same timeframe, the Chief Medical Officer (CMO) for the

eHealth Initiative in Washington, DC spoke on the idea of a National Health Information Network (NHIN). The CMO states "I think the NHIN will fail miserably if we don't solve the trust issue around Internet communications. I believe that the NHIN must be built on top of the Internet and that eventually, every communication on the NHIN must be secured." The CMO elaborates further citing issues such as security, authentication, non-repudiation, auditing, encryption and transport. He concludes remarking that "Many communities are now going through the growing pains to discover and implement the sustainable business models necessary to support regional health information exchange with the expectation that the results of their efforts will be higher quality, more efficient healthcare that results in fewer medical errors. Privacy and security concerns, however, can overwhelm such efforts if they are not addressed fully, and it is clear that incomplete and fragmented security will not satisfy anyone with privacy concerns." It is obvious by all accounts that HIPAA is a challenge.

Enter technology. It is common knowledge that the Electronic Health Record is upon us. Albeit a fragmented technological quagmire of multiple visions of the truth, it is here. There is a very compelling article (non-scientific) published by a reporter in Washington[vi]. It is appealing because it speaks not only to a specific Health Information System (HIS) vendor (which is not the intent here), but, moreover, illuminates the fragmentation of information, even across any given vendor's implementation of their product. If we ponder this momentarily, and then add one of the rising stars Internet of Things (IoT) to this already complex equation, we quickly understand from a technological standpoint another challenge. Medical Health & Life Science Research News[vii] reports on the growing presence of IoT in the medical industry and predicts phenomenal growth over the next five years. HIS vendors have historically ignored data analytics and today still fall notably short of what researchers and other industries consider routine. HIS vendors, still behind the proverbial curve of analytics, are now scrambling to assimilate IoT into their myriad of tricks. Given the engineering nuances associated with IoT[viii] for healthcare, and the fact that HIS vendors are behind the analytics 'eight ball,' we need to ask ourselves when and how this will come to fruition for HIS participants. We should also be cognizant of where HIS vendors have specialized their contributions and challenges. HIS vendors historically focused on capturing and delivering data geared towards healthcare day-to-day operations. This includes two dimensional reporting, charting, etc. Their focus has not been hardcore analytics; such things were left to researchers, data scientists and informational technology. HIS companies require time to assimilate this new set of tools into their core set of competencies. As most of us realize, data science is not for everyone and is not something to be taken lightly.

Enter data science. With a plethora of data, from the continuum of the Electronic Health Record, IoT and whatever academicians can dream up next, we often wonder how we store, consume and innovate from this sea of data tranquility. Following the notion that from data comes information, and from information is derived knowledge, and knowledge leads to innovation, we analyze it[ix]. Across the country many of the prominent academic institutions are forming "Data Science as a Service" offerings led by exceptionally qualified personnel. This is a spin on "Service-Oriented Science" which promotes a wider range of scientific widgets beyond pure mathematical[x]. Such services offer healthcare institutions, without such credentialed academicians, the opportunity to leverage current data science techniques.

Enter tangential industry experience. Beyond healthcare EHR's, data swamps, and statistical prowess, there is another inviting avenue that has promise to aid in the assimilation of the vast amount of information available. Industrial companies have a huge foothold on the IoT space and employ many

advanced statistical and machine learning algorithms on static as well as streaming (in flight) data[xi]. Healthcare in general should take a very close look at the forerunners in this space and adopt as opposed to 'reinventing the wheel.'

Discussion and observations. We know from experience and academia that the holy grail of the HIE, albeit difficult, is not insurmountable. We also know that technology is by and large the least inhibiting factor; monetization, politics, law, acceptance and trust are but a few of the major attenuators of success. It is also readily apparent that the major HIS vendors are not going to provide a solution (in the near future) because they are too focused on providing their core competency - the day-to-day operations of healthcare. Moreover, the major HIS systems do not communicate on a level that facilitates completely integrated and seamless information flow, nor is this their problem alone to solve. Beyond the data continuum lies the quest for medical predictive outcomes, learning algorithms and unified Protected Health Information (PHI). Many of the teaching healthcare and prominent Technology institutions are engaging in research and systems that will facilitate the eventual fruition of the national HIE dream. In the interim, healthcare members should strive to organize their data and find ways to integrate IoT, if applicable. Given the Data Science as a Service Resources now available, it is not mandatory to staff internal data scientists to become analytically savvy. Furthermore, looking toward other industries, specifically those involving IoT, may provide many inroads for healthcare; learn what has been learned. A few steps for each organization, specifically around organizing data, will significantly streamline HIE efforts. The premise of this writing is to instill the notion that a 'centralized' body of knowledge may be obsolete; many organizations collaborating in a digital medical collective seems more appropriate, sustainable and secure[xii]. In order to achieve such a goal, each organization needs to organize their information and collaborate; this idea is not new and has undergone many transformations[xiii].

Conclusion: Enter the dream.

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