Innovation Valley (www.ivalley.org)

Ease Their Pain ... with Information-Based Medicine

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The names have been changed in this true story to protect the patient and his family, and the healthcare providers that served them.

Joshua was very fit at 80 years young until cancer was diagnosed – his life and that of his family would never be the same again. The saga begins with his daughter providing a handwritten list of fifteen medications that he was taking for various other illnesses upon his initial admittance into the hospital for a battery of cancer-related tests. The information appeared to be typed into a computer during the admitting process, but it was not forwarded to anyone. A black hole came to mind.

A week later, when the tests were completed, Joshua returned to the hospital to see his cancer doctor to review the tests. Joshua's family was again asked to provide a medication list to the doctor's nurse who then rewrote the list by hand. The doctor asked the nurse to revise the list of medications based on the test results and his diagnosis, despite not knowing the basis for many of the original fifteen medications which were prescribed by a variety of specialists.

There where no notes from the specialists and no consultation calls. The only explanation of previous visits to the specialists was provided by the patient and perhaps someone in Joshua's family, who may have taken him to the appointments with the specialists. In some cases, the cancer doctor eliminated some of the original medications because they clashed with some of the new medications being prescribed. Joshua and his family began to wonder who, if anyone, had the big picture view of his medical condition.

On a subsequent trip to the emergency room (ER) at the same hospital due to complications from the cancer, Joshua's family was again asked to provide the revised list of medications during the admittance process. Again, the information appeared to be typed into the computer, but was not sent to anyone. However, this time a printout was carried by a "runner" to the ER nurses and doctor.

After an examination and review of the test results, the ER doctor tried to diagnose Joshua's acute symptoms without the detailed history and rationale for many of the medications prescribed by the various specialists. Notably, the ER doctor did make a consultation call to the cancer doctor, since both worked at the same hospital. Still, the ER doctor was forthright with the uncertainty in his diagnosis leaving Joshua and his family very anxious.

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The ER doctor then updated the list of medications once again based on his diagnosis. The ER nurse crossed out some medications on the list and added some new ones. This became the list of record to be transported by Joshua and his family. It was a major burden during a time of duress for Joshua and his family to be responsible for providing the list of the medications to each health provider, especially to be queried about the rationale for the medications.

Over the course of the next few months, the cycle was repeated many times as Joshua was checked in and out of ERs, hospitals and clinics for care numerous times and visited several physicians, including the cancer doctor, a variety of specialists, his primary care physician and the radiation doctor. It was hit or miss with physicians in terms of how closely they coordinated with all of the other medical professionals associated with Joshua's health conditions. In many cases, there were time and technology constraints, as well as corporate business, legal and regulatory barriers that prevented collaboration amongst the key stakeholders.

Unfortunately, at the end of this rigorous and sometimes haphazard marathon, Joshua passed away. While his family agrees that a better medical process would not have saved their father's life, better medical processes and information technology (IT) tools may have extended his life and eased his pain during the ordeal, and would have lessened the wear and tear on the family.

Many community hospitals, like those in the Merrimack Valley, have recognized these shortfalls, and are in various stages of improvement. While the medical centers in big cities like Boston generally have more modern health delivery processes and IT tools, they too have much room for improvement. The challenges involved are not trivial.

Potential Solutions

IBM, in conjunction with the healthcare industry, is the early leader in helping to better connect the various stakeholders in the healthcare delivery process by enabling information-based medicine. The Personal Health Record (PHR), an individual's health record stored in an electronic file, is a key building block for the solution. It directly addresses the problem of creating, maintaining and accessing an accurate list of medications on-demand, as well as a detailed history of test results, examinations by medical professionals, diagnoses and status.

Together with electronic collaboration tools, such as secure email, the PHRs can help connect the various medical providers in the end-to-end healthcare delivery system with each other and to the key information that they need on-demand to make sound medical decisions.

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This all sounds easy to do in this electronic age; yet nothing could be further from the truth. The adoption rate for PHRs has been low so far. As a consumer, you are most likely to create and manage a PHR through your health plan provider. They are best positioned to establish a user-friendly, secure web-based service for you to implement a PHR. They must coordinate with all the providers in each customer's healthcare delivery system, traversing many organizations, with business, legal, regulatory and technology interoperability barriers. The web-based PHR must be compatible with and easily accessible from all the pertinent stakeholders.

The biggest barrier to adoption of web-based PHRs is clearly privacy. Privacy issues in healthcare dwarf similar concerns that consumers have with electronic financial transactions. Every consumer is concerned about the wrong person or organization acquiring knowledge about their health history or status and using it against them. And it's not just hackers that they are worried about.

Many organizations may legally have access to a patient's information – but who will have access within the organizations, under what controls, and how will the information be used? Many controls and substantial education are needed to spawn adoption.

To make matters worse, the web-based PHR faces the same hurdles that every software product manager faces – it must be user-friendly, with a strong value proposition for the consumer to devote the time to learn how to use it. Then, the value proposition must be marketed, so that the consumer can be made aware of the benefits.

Our Recommendation

We recommend that the Merrimack Valley healthcare community band together and develop a pilot to introduce information-based medicine to the region. There are many success stories that we can build from – visit www.ibm.com for case studies. There are likely examples from the network of world class hospitals in Boston that can be used as models. Further, there are examples of initial efforts in the Merrimack Valley healthcare community that should be leveraged.

It is clear that a broad-based working group of all key stakeholders, including patients, will need to work together to ensure that the unfortunate sequence of events endured by Joshua and his family will not be repeated.

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The Innovation Valley initiative seeks to help stimulate economic growth and quality-of-life enhancements in the Merrimack Valley. Every month we will report on innovative businesses, practices, and ideas that are helping to make Merrimack Valley the place to be. Look for our article in print media and online at www.ivalley.org.