Paul Harvey, one of the best-known Twentieth Century radio newscasters, was famous for telling “the rest of the story.” He used this regular feature to bring attention to an overlooked detail or little-known fact, helping to bring new meaning to major news events of the past. Often, an old story suddenly made more sense or seemed more interesting because of his addition of new information.

As a futurist, I’m going to step out on a limb with this column and foretell “the rest of the story” behind the articles in this issue of JHIM. It is about a special point that must be understood and an action that must be taken before the final story can be told, probably sometime between 2010 and 2015.

Today’s HIT Story

The ongoing development of a seamless IT enterprise is good and timely news; it is well worth a special collection of articles that explore integration and interoperability from different perspectives. However, it has been covered for many years, and the roadblocks to a seamless system continue to be a big part of the story. Problems with interoperability might not be making the news today if the sole source movement had decisively won its battle with best-of-breed in the 1990s. Way back then, many healthcare IT vendors offered visions of fully integrated applications that would automatically “talk to each other.” Hospitals liked the concept of fully integrated software that spanned the enterprise’s clinical, financial, and operational data.

However, these purchasers often concluded that key components of the soon-to-be seamless systems were less robust than freestanding modules dedicated to only one business process. They also feared—rightly, in retrospect—that many of the promised interactive functions would fail to materialize. Remember “vaporware?”

In the absence of incentives or mandates for seamless systems, best-of-breed solutions survived long enough to be rescued by improvements in storage and software. Dramatic declines in the cost of data storage, improvements in the processing power of computer chips, and rapid advances in connectivity enabled developers to work around incompatible data formats and closed operating systems.

Web services and service-oriented architecture subsequently have emulated interoperability, providing new hope for virtually seamless interaction between closed systems. Indeed, best-of-breed and interoperability were arguably viewed as...
mutually exclusive concepts as recently as two or three years ago. Using middleware to open formerly closed systems has enabled the creation of regional health information organizations (RHIOs) and similar projects, laying the foundation for a national health data infrastructure.

Such remarkable and unexpected progress toward seamless networks might lead some observers to conclude that the HIT story is nearly complete and that the promised land of integrated systems lies just around the corner. This view is quite likely to be wrong. It overlooks a major problem that will not be solved just because different vendors’ closed, proprietary systems can be virtually interoperable.

The Missing Link

Integrated information systems won’t solve the problem of disintegrated patient records. That’s because any individual patient’s health information is widely scattered across space and time. A complete file of patient-specific data simply does not exist in any format that can be uniformly merged in virtual space, regardless of any achievement of technical integration and interoperability.

If further evidence is needed to substantiate this entropy—defined by physicists as information in a system not available to do work—in the realm of patient records, consider how many databases you would need to mine just to extract all your own health information. Then imagine the difficulty of putting it all in one location that could be universally retrieved and meaningfully interpreted by any provider organization where you might seek healthcare.

Interoperability would be a very helpful tool for negotiating some of the interfaces, but it would not easily overcome problems like resolving different versions of a patient’s name; accessing data stored on paper forms or records held by providers outside the network; or listing the use of alternative therapies, such as herbal supplements that interact adversely with prescription medications or body manipulations by unlicensed practitioners. HIPAA also would complicate the amalgamation of all these data, even if they could be retrieved electronically. In other words, many important elements of a complete medical record are beyond the reach of a seamless system.

The problem will not be solved until patients are empowered to create and maintain their own comprehensive medical records in system-accessible formats. The technical specifications of patient-managed medical records need to be developed.

Fortunately, the concept already has been put into practice. A few commercial Web services and progressive employers already provide individuals with the structure and tools for creating their own Web-based health records. This initial work needs to be expanded and integrated into the seamless IT system.

The patient-managed, virtually organized health record is the missing piece in a seamless system that meets our long-term expectations for healthcare information technology. Integrated IT systems will fall short of expectations until the patient is brought into the loop as the integrator of all personal health information.

Challenges Ahead

The shift from provider-controlled to patient-integrated information will not be easy or fast, but it must be promoted as a key to the seamless system sought by all. It deserves at least as much policy attention as RHIOs. Demonstration projects should be launched as soon as possible so problems can be identified and solved sooner rather than later.

This solution will not develop on its own; it is not part of the current plan. However, it is fully consistent with the accelerating shift from employment-based insurance to consumer-directed healthcare. Further, empowering patients to own, literally and figuratively, their health information increases the likelihood that providers will have all the information they need to give more patients the care they want.

Of course, many patients will not have the skills or resources to compile their own health records, which is a consideration that will raise ethical issues. Other roadblocks will pop up along the way, but they should not prevent progress.

When the digital transformation to seamless healthcare can finally be reported, the development of patient-controlled health records will not only be the rest of the story; it will be one of the most important parts of the story.

About the Author

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