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Health Information Exchanges: Patients Must Be Convinced

HIEs need more than consistent standards and cooperative healthcare providers. Patients must get on board--and the right kind of PR can win them over.

By Paul Cerrato, [InformationWeek](#)
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While health information exchanges (HIEs) have the potential to save Americans millions of healthcare dollars, getting these patient data-sharing services up and running has become a tangled web of regulations, conflicting IT standards, and provider resistance.

They also face a significant challenge when it comes to getting patient buy-in. The College of Healthcare Information Management Executives' [guide to HIEs](#) outlines two approaches that providers can use to obtain patient consent, namely opt in or opt out. Regardless of which approach your organization uses, it needs to be sensitive to the public's fears.

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As I mentioned in [my last column](#), the public is afraid that their medical data won't be safe. And given the number of [data breaches](#) in the news recently, you can certainly understand their concerns.

[**Legally, electronic health records are double-edged swords: They protect clinicians from malpractice litigation but also put them at greater risk. See [Will Your EHR Land You In Court?](#)**]

But those breaches tell only part of the story. And the rest needs to be told if the health IT community ever hopes to convince people to let HIEs use their personal data.

The federal government spends a great deal of money in professional journals hoping to [convince health professionals](#) of health IT's value. It's time to direct some of that cash at the general public. A PR campaign aimed at consumers will likely ease their security concerns, but only if it's deftly handled.

The [Office of the National Coordinator for Health IT](#), for instance, could run ads in *People*, *Self*, *Parade*, and similar consumer magazines, or on healthcare websites like WebMD.com, Medlineplus.gov, or Medicinenet.com, talking up how digitizing a person's medical information would speed medical treatment and help protect a patient from harm by maintaining details on medications, allergies, and medical issues.

To be effective, the campaign can't just discuss these issues in the abstract. It would have to counterbalance all

the scary stories about identity theft and data breaches with emotionally moving success stories about real patients who benefited from health IT and HIEs.

Clinical thought leaders and health IT executives tend to stick to the facts, offering a dispassionate, statistics-filled defense of HIT. But the public is never going to be won over with statistics alone.

All you have to do is look at the debates in the consumer press about the latest health scare to appreciate the fact that people respond to narratives more than to hardcore evidence. They're far more likely to be swayed by a heart-wrenching story of a child who developed autism after being vaccinated against measles, for instance, than by the mountains of research data that have failed to establish a cause-and-effect relationship between autism and vaccines.

With that in mind, health IT leaders have to think in terms of what Zarchy Meisel, MD, and Jason Kalawish, MD, from the University of Pennsylvania call [counternarratives](#).

Here's one such counternarrative: "During John Martin's last business trip, he found himself in an ER 2,000 miles from home, too disoriented to even provide his medical history, let alone remember that he's allergic to penicillin. Fortunately, the doctor on call was able to access all that information because his records were available from the National Health Information Network."

Another one worth considering: "Mrs Diaz recently had her identity stolen and had to spend countless hours coping with all the legal and financial complications. It turns out the thief gained access to her confidential information by stealing a patient chart from a file cabinet in her doctor's office while his staff wasn't paying attention. This situation could have been prevented had all the doctor's records been digitized."

Granted, IT professionals and clinicians shy away from such anecdotes because by themselves they prove nothing--and many thought leaders feel they're a dishonest means of persuasion. But when you line up this type of story alongside solid data, there's really *nothing* dishonest about it.

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