

DEBATE: PART III

Let Patients Help

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Of the many ways a clinician creates value, few can be automated. Delivering lab results can.

Mind you: final *interpretation* of the data will always require the physician's trained mind. But the delivery itself—with user-friendly formatting and appropriate reference values—should be removed from the busy physician's back.

It might have saved Pat Sheridan.

In 1999, Sheridan had a tumor removed from his neck.² The surgeon said it was benign, and pathology agreed, two weeks later. But a later report was filed accidentally without ever being read: cancer. Malignant sarcoma.

Three years later Sheridan was dead, and *still* nobody had seen the report—until his wife Sue asked for the chart. What if she'd seen the report back then?

That was 1999, the year *To Err is Human* was published. Twelve years later, a well publicized article documented that 7% of all lab results still go undelivered. One in 14. We pay for these tests; can't we ensure delivery?

The common objection is that patients won't understand, they'll get scared, and physicians' phones (or e-mails) will be overwhelmed with problems nobody needs. After all, the reasoning goes, lab data is a mess of numbers, and great skill and experience is needed to know what they mean.

In September, this was articulated by J. Fred Ralston, MD, former president of the American College of Physicians, in *Information Week*:

"Lab results often contain a lot of information. A patient downloading many raw lab results over the Internet may be overwhelmed by lots of tiny insignificant abnormalities that could each demand an individual explanation—and cause significant worry until those concerns are dealt with."³

He's right: A pile of raw numbers, with ugly formatting (or none), will not sit well with many patients. But that can be solved (more on that in a moment), and even ugly numbers are fine for today's engaged and empowered e-patients. More on them below, too.

Besides, it's not about the data—it's about the knowledge.

*Where is the wisdom
we have lost in knowledge?*

*Where is the knowledge
we have lost in information?*

—T. S. Eliot, *The Rock* (1934)⁴

*Information is not knowledge,
Knowledge is not wisdom,
Wisdom is not truth.*

—Frank Zappa, "Packard Goose"
(*Joe's Garage*, 1979)

The "DIKW" model asserts a hierarchy of knowledge. Each level adds meaning: Data to Information to Knowledge to Wisdom.⁵

The gulf between data and wisdom is vast, and in medicine that matters. Some patients—the engaged ones—are savvy about their labs, but others have no clue. If lab results are raw data, who will add meaning and context? Today the clinician bears all the burden, not just for interpretation but for communication. A mistake in either task is a medical error: an error of interpretation or a dropped ball in communicating, such as Pat Sheridan. Is it sensible to put both burdens on the physician's back? Can't we modernize?

In their famous 1972 *NEJM* paper "Patient-computer Dialogue," Slack and Slack presciently noted the need for physicians to work at the top of their pay grade, decades before Lean said it's the modern thing to do:

Doctors as interviewers are busy, ex-

pensive and sometimes hard to find. It seems reasonable, therefore, to look for substitutes that will serve at least some of the purposes of medical interviewing in widespread and inexpensive ways.⁶

The article proposed automating getting data *from* patients, but it works the other way, too. Indeed, if docs are busy and hard to find, that alone could explain the failure to deliver one in 14 results.

Should we whip clinicians for this? I think not: As IHI's Jim Conway often says, "Our systems are too complex to expect merely extraordinary people to perform perfectly 100% of the time. We as leaders must put in place systems to support safe practice." And of all the burdens clinicians must bear—seeing more patients in less time, keeping up with the literature, restructuring for accountable care organizations and meaningful use—the last thing I'd give them is a task computers can do easily, accurately, and reliably.

So now we come to the DIKW challenge: Most patients can't extract knowledge from row after row of numbers. Indeed! Labs don't deliver the information in a way that gives consumers knowledge.

The first financial printout I ever got from an insurance agent was a few years after Slack and Slack. It was an ugly stack of greenbar paper, and I'm sure there were financial analysts who said consumers were unqualified to absorb it. Today no investment advisor could survive that way; to the contrary, they compete based on the slickness of their charts. Innovation has come to the presentation of their data.

So it's no surprise that when *Wired* executive editor Thomas Goetz received a report from his doctor's lab that resembled greenbar, he

continued on page 2

took it to his artists and asked, “Can’t we do better?” They produced a new design that was so good, the story was selected for the prestigious TEDMED conference. His values are printed along green-yellow-red scales, with pie charts and automated “See your doctor” highlights for out of bound values.

Still, what about the patient who freaks out at numbers in red? I hear Jack Nicholson: “You can’t *handle* the truth.” To that I quote my testimony to a 2010 Meaningful Use policy meeting: “Until people gain experience, they’re inexperienced. The solution is not to restrict and constrain. Empower the people: enable, and train.”

“Well, you’re abnormal,” physicians sometimes tell me. “My patients don’t ask for this.” Indeed, in high-tech marketing we know there’s little demand for something until people know it’s possible. So we publicize. We put signs in our storefronts; we put “New!” on our websites. If you do that and still nobody asks, then we’ll talk.

Meanwhile, even without the ads, the Pew Internet and American Life Project notes that about 16% of online adults already seek information about test results they’ve received.⁷ And the “e-patient” movement—empowered, engaged, equipped, enabled—has spawned a Society for Participatory Medicine.⁸

Why do we anticipate the development of friendly software for complex data? Because that’s what happens when new data streams are opened to innovators: They compete. They try to please. Look at other in-

dustries—weather, airlines, finance—with their extraordinary range of data visualization tools, developed by entrepreneurs.

One difference is that those industries have rich and robust data streams, readily accessible to innovators. Not so in medicine—until now. But it’s begun: an ecosystem is already developing around the Blue Button “download my data” initiative, started in 2010 by the Markle Foundation, initially supported by the Veterans Administration and Centers for Medicare & Medicaid Services and now endorsed by a dozen organizations.⁹ Adopters include TRICARE (the military health system) and data formatters ranging from PatientsLikeMe to Aetna and United Healthcare. On November 19, US Chief Technical Officer Aneesh Chopra announced that Blue Button software will soon touch 100 million US lives. That’s the kind of market size that spurs innovation... software that converts data to information to knowledge.

In the end it comes down to caring for lives. My marketing antennas attune me to shifts in the wind—telltale signs of change or resistance. And I’ve found that while some don’t care about my right to *my* data, hardly anyone objects to parents being hawk-eyed about their children’s health. The same goes for adults who care for their “aging in place” parents. What a tragedy it would be if an important lab result failed to reach such an avid caregiving family member.

Like Sue Sheridan.

Indeed, in Pew’s Health Topics report, among the most likely to

seek information on test results are caregivers and patients with chronic conditions.

So if you still find yourself skeptical about sending me my data directly, consider the grandchildren I hope to care for some day, and consider my mom in Annapolis. For them, “We’ll call you if there’s anything wrong” is not enough.

Let clinicians apply their skills and wisdom to the tiers of care that only they can provide. For matters where patients can carry a load, please let us: Give us our data. Let patients help.

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