Feature Story
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Medical Records: Human Lives in the Balance

"I constantly have to lug records around with me," says Melissa Santini, the

Florida mother of Rocco, a chronically ill toddler. "Nobody is interacting. I'm so

overwhelmed by all the information, paperwork, blood tests, hospital visits

. . . I am beyond frustrated."

Melissa is not alone. When American patients—in all disease groups, from all

walks of life, ages and incomes—enter the healthcare system, they step out of the

familiar 21st century information economy into a world managed by paper, phone calls,

snail mail, even yellow-sticky notes. While banks, airlines and retail outlets manage

accounts, flights and inventories in real-time, the healthcare sector mires doctors and

patients alike in a paperwork shuffle.

Consider the plight of Gay Quick of Missouri, whose late husband struggled

against a brain tumor for 19 years. After filling out countless forms and questionnaires,

Gay says, "I finally wrote down everything, so when he went to the doctor, I would

take my satchel…Tommy's life was in my satchel."

Tommy's illness was a nightmare enough—100 MRIs, many rounds of

chemotherapy and multiple brain surgeries, receiving treatment from three hospitals

across the nation. Added to it was the stress imposed on Gay as she had to take it upon herself to keep track of Tommy's doctor visits, medications, insurance information and all of his MRIs. When the tumor began to grow rapidly, the Quicks needed to get an MRI from Kansas City to specialists in San Francisco. They were told it would take up to a few weeks to mail the MRIs. So, Gay did it herself - sending all the MRIs by overnight mail and making a series of calls to confirm they were received.

Keeping up with the piles of documents and memorizing countless pieces of information can be challenging and – all too often – extraordinarily trying for patients and loved ones. Out of frustration, some physicians are beginning to build their own information systems. On the day Vioxx was recalled, Dr. Robert Lamberts, a Georgia physician, searched his electronic medical records system for patients taking the drug, and immediately sent each of them a letter to inform them of the recall. Though patients were amazed, Dr. Lamberts was merely relying on the same information technology that other U.S. businesses routinely use. "The computer doesn't cut out on the time you're talking to your patient," Dr. Lamberts says. "If I can have information at my fingertips, I can spend much more time caring for my patients."

Dr. Lamberts cautions that it is not enough for individual practices to keep electronic medical records, so long as clinics, hospitals and other facilities cannot share information across technological barriers. "If you're going to create a paperless system

like the banking industry, where one bank talks to the other and the information can go seamlessly from one bank to the next, the only way to do it is to have interoperability."

The costs imposed by the lack of an interoperable healthcare information network are huge. If healthcare providers could quickly access and share secure information about medical history, drug sensitivities and prescriptions, billions of dollars in waste could be saved. With medical errors claiming more American lives than AIDS, breast cancer or motor vehicle accidents, good information could also save thousands of lives.

> The point was brought home for Jeanne Canfield of South Carolina, whose husband, Dave, is an elderly man with a pacemaker. Due to a lack of easily available electronic health information, Dave had two close calls with death. The first time, Dave was sent to the waiting area for an MRI before he happened to learn that the technology would cause his pacemaker to shut-off, killing him. On another occasion, his wife Jeanne was unable to read the handwriting of Dave's doctor instructing him to stop taking a blood-thinner before surgery. Dave took the blood-thinner right up to the date of his operation—an oversight that was caught by the hospital staff prior to the operation. The Canfields were fortunate; at one point, Jeanne says, "We got in the car and my husband looked at me and said, 'I could have been dead.'"

The lack of sharable information affects many patients, including Melissa's ailing toddler, Rocco, who has had to repeat invasive tests when seeing different doctors. Unfortunately, this is far from unusual. In fact, some 20% of medical tests are ordered a second time because previous results cannot be found.[i]

People are also paying a price in fear—the fear that they will forget a piece of information that will cause them or their loved one to die. Consider 22-year-old Ashley Shaff, who has been the patient of at least 36 doctors, hospitalized over 35 times in a dozen different hospitals around the nation. Ashley is missing a critical gene. This missing gene caused a hole in Ashley's heart, a lack of growth hormone and a narrowing of the arteries in her lungs.

Fortunately for Ashley, her mother, Peggy Frank has managed her daughter's care from the moment she was born. She keeps track of her extensive and complex medical records stored in boxes, binders and personal memory, dating back to eye surgery at the age of nine months.

Peggy's list of her daughter's medical procedures includes heart surgery, two adenoid surgeries, four cardiac catheterizations and three pulmonary angioplasties. Keeping order in this jumble of critical information is a source of frustration and desperation for Peggy—and a danger for Ashley.

As the volume of Ashley's medical records grow, it becomes more challenging for Ashley to play the "document game." Peggy is left to keep track of every detail in order to retell her daughter's medical history during even the most stressful times. She must recite it over and over—hundreds of times—because Peggy is the only source of

information that follows Ashley from city to city, hospital to hospital and emergency room to emergency room.

"I couldn't be left alone with my thoughts and pain," Peggy says, "instead I was forced to regurgitate a horrific medical journey once again." In addition to providing an oral history, Peggy transports binders filled with laboratory reports, X-rays, medication lists and medical reports. Despite Peggy's best efforts to accumulate all the relevant data, she worries that she has forgotten or is missing crucial information.

A study in the Annals of Family Medicine found that 80% of "error chains" in medical cases result from miscommunication between physicians, misinformation in medical records, mishandling of patient requests and messages, inaccessible records and inadequate reminder systems. Studies also show the United States could save much of the $200 billion in estimated annual costs due to injuries caused by medical mistakes. The unwieldiness of paper is a crisis for a nation that has more than 500,000 office-based physicians, about 5,000 community hospitals, more than 16,000 certified nursing facilities, and many other care settings.[ii] Dr. Robert Fried, a North Carolina physician, reports that every year his practice has to spend more on transcribing medical records than what it would cost to establish electronic medical records.

Only an electronic information exchange could allow so many caregivers to keep the records of hundreds of millions of Americans. It could also help doctors to focus more of their attention to patients, instead of paperwork.

Dr. James Morrow implemented an electronic medical record system in 1998 at his North Fulton Family Medicine Practice in Cummings, Georgia. This move alone cut more than $32 from the cost of tracking patient records on paper. The savings have enabled the practice to see three times the number of patients.

"The big thing is we can practice better medicine," Dr. Morrow says. The staff at North Fulton Family Medicine can now alert patients when medications are recalled, receive reports in a secure electronic fashion, track tests and procedure results, better communicate internally, and for patients with chronic diseases, it is possible to track their visits and know when they have missed a visit that could be vital to their care.

For all these reasons, strong bipartisan support is building to give American healthcare the same level of information technology that banks, airlines and retailers have enjoyed for years. President Bush has outlined a vision of providing most Americans with such records within ten years. To get the job done, Congress mandated the creation of the Commission on Systemic Interoperability—11 medical, insurance, governmental, technological and corporate leaders tasked to come up with

recommendations, priorities and a timeline for the adoption of privacy-protected

systems of electronic health information.

      With so much at stake, the Commission's report, due in October, should end the

debate and set the basis for action.

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[i] Sen. Jon S. Corzine, 5/23/2005; Center for Information Technology.
[ii] Cited by David J. Brailer, *Health Affairs,* Jan. 19, 2005, "Interoperability: The Key to the Future Health Care System." American Medical Association, *Physician Characteristics and Distribution in the U.S., 2004–2005 Edition* (Chicago: AMA Press, December 2004), 63, Table 3.1; American Hospital Association, "Fast Facts on U.S. Hospitals," 2003, www.hospitalconnect.com/aha/resource_center/fastfacts/fast_facts_US_hospitals.html (11 January 2005); and American Health Care Association, "Trend in Certified Nursing Facilities, Beds, and Patients," www.ahca.org/research/oscar/trend_graph_facilities_beds_patients_200406.pdf (11 January 2005).