

The no-computer virus

Costs, compatibility and patient privacy have all been cited as reasons why patient records cannot be computerised. But the inability, and reluctance, of doctors and hospitals to use information technology more widely is killing thousands of people.

Whether or not a treating doctor has Alex's full medical record available can literally mean life or death," says Cynthia Solomon of Sonoma, California. Her son Alex, now in his 20s, grew up with hydrocephalus, a rare and life-threatening condition in which fluid accumulates in the brain and needs to be drained through special shunts. So Ms Solomon had no choice but to become a walking filing cabinet of records on allergies, pituitary-gland problems, brain scans and "every piece of paper a doctor ever wrote about Alex's case." She worried constantly. There were close calls, such as the time that Alex went on a trip and ended up, unconscious, in some distant hospital. Ms Solomon could not get his paper records to the new doctor and had to pray that Alex would not get the wrong antibiotics or be laid on his back, which might have killed him.

To Ms Solomon the information problem with health care today is so glaring that she eventually took matters into her own hands, as best she could. She took out a second mortgage, hired software programmers and developed a computer system, called FollowMe, for online medical

records that any doctor can, in theory, access anywhere and anytime. FollowMe will not fix the world's health-care industry – only about 400 families now use it – but Ms Solomon has correctly identified the woeful, even scandalous, failure of the health-care industry worldwide to adopt modern information technology (IT).

The solution seems obvious: to get all the information about patients out of paper files and into electronic databases that – and this is the crucial point – can connect to one another so that any doctor can access all the information that he or she needs to help any given patient at any time in any place. In other words, the solution is not merely to use computers, but to link the systems of doctors, hospitals, laboratories, pharmacies and insurers, thus making them, in the jargon, 'interoperable'.

This may be obvious, but today it is also a very distant goal. According to David Bates, the head of general medicine at Boston's Brigham and Women's Hospital and an expert on the use of IT in health care, the industry invests only about 2% of its revenues in IT, compared with 10% for other information-intensive industries. Superficially, there are big differences between



US President George W. Bush looks at an electronic medical record system during a visit to the Cleveland Clinic in Ohio, January 27, 2005. One estimate suggests that IT could prevent 2 million adverse drug interactions and 190,000 hospitalisations in the US every year

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countries. In Britain, 98% of general practitioners have computers somewhere in their offices, and 30% claim to be 'paperless', whereas in America 95% of small practices use only pen and paper. But, says Mr Bates, this obscures the larger point, which is that even the IT systems that do exist cannot talk to those of other providers, and so are not all that useful.

It shows. People on the right side of the digital divide increasingly take for granted that they can go online to track their FedEx package, to trade shares, file taxes and renew drivers' licences, and to do almost anything else – unless, of course, it involves their own health. That information, crumpled and yellowing, is spread among any number of hanging folders at all the clinics they have ever visited, and probably long since forgotten about. The most intimate information is, in effect, locked away from its owners in a black box.

Many IT bosses find this baffling. John Chambers, the chief executive of Cisco Systems, the world's largest computer-networking company, says that health care is down there

with mining as the most technophobic industry. Jeff Miller, a manager at Hewlett-Packard (HP), a large computer-maker, calls health care "one of the slowest-adopting industries", which is especially surreal because hospitals often splurge on the latest CAT-scan or MRI equipment, but are stingy with their back-office systems. It is, he says, like "Detroit putting out futuristic hydrogen cars but using paper processing and manual labour for the manufacturing."

This has perverse consequences. According to the Institute of Medicine, a non-governmental organisation in Washington, DC, preventable medical errors – from unplanned drug interactions, say – kill between 44,000 and 98,000 people each year in America alone. This makes medical snafus the eighth leading cause of death, ahead of car accidents, breast cancer and AIDS. "It's like crashing two 747s a day," says Mark Blatt, who was a family doctor for 20 years before he joined Intel, the world's largest semiconductor-maker, to manage its health-care strategy. There should, he says, be more outrage.



Medical records awaiting transfer onto computer. Britain, Spain and Denmark are pioneering national/regional networks for electronic patient records. Much of Europe, however, remains more like the US, where 95% of small practices use only paper and pen

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RICH PICKINGS

Improving computer systems, of course, would not eliminate all medical errors. But most researchers believe that they would reduce them dramatically. One study in America estimates that IT could prevent 2 million adverse drug interactions and 190,000 hospitalisations a year. Another study reckons that electronic ordering of drugs can reduce medication errors by 86%. By contrast, research published in March in the *Journal of the American Medical Association* warns that IT, if the software is badly designed, could actually increase errors. But almost everybody agrees that well-designed IT is essential to improving quality in health care.

The same goes for its cost, an increasing burden to ageing societies in the rich world and even in poor countries such as China. HP's Mr Miller reckons that redundancy and inefficiency account for between 25% and 40% of the \$3.3 trillion the world spends on health care every

year, and could be eliminated with proper IT. A study from a clinical research centre at Dartmouth College in New Hampshire reaches a similar conclusion, estimating that a third of America's \$1.6 trillion in annual health-care spending (as of 2003) goes to procedures that duplicate one another or are inappropriate.

Estimating how much IT could save, after taking account of the considerable cost of applying it widely, is not easy. Writing in *Health Affairs*, an American journal, in January, Jan Walker and five colleagues (including Mr Bates) at the Centre for Information Technology Leadership in Boston concluded that a fully interoperable network of electronic health records would yield \$77.8 billion a year in net benefits, or 5% of America's annual health-care spending. This includes savings from faster referrals between doctors, fewer delays in ordering tests and getting results, fewer errors in oral or hand-written reporting, fewer redundant

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tests, and automatic ordering and re-fills of drugs. It does not include, however, perhaps the biggest potential benefit: better statistics that would allow faster recognition of disease outbreaks (such as SARS or avian flu).

The key word in all such estimates is always 'interoperable', says Mr Bates, pointing to the differences between two pilot programmes in America. In one, the Californian city of Santa Barbara set up a city-wide peer-to-peer network (in which the computers of different practices and clinics can talk directly to one another). This allows doctors, say, to pull up portable-document-format (PDF) files from one another. But the information in them – text, with numbers buried in it – is 'unstructured' and so not very useful. It is the equivalent of faster faxing, and not what people mean by interoperability.

The other American pilot, located in Indianapolis and managed by the Regenstrief Institute, a non-profit medical-research organisation, comes closer. It has created a city-wide network in which physicians can, with the patient's permission, log on to a complete medical history that includes all previous care at the 11 participating hospitals. Already, the database contains 3 million patient records, 35 million radiology images, 1.5 gigabytes of diagnoses, 20 million order-entries by physicians, and so forth. The key difference is that, wherever possible, the data is entered in a structured and formatted form. Test results are in neat rows and columns and tagged in a way that every other computer can recognise and compare against other appropriate numbers. This is the sort of IT solution that not only cuts waste and errors, but also helps physicians to make better decisions.

What, then, would the ideal IT architecture of health care in future look like? It would start, says Intel's Mr Blatt, with wireless data entry by nurses and doctors. Practices and clinics would have secure 'Wi-Fi hotspots' – using a radio

technology called 802.11 – and staff would walk around with small handheld devices that transmit all inputs to the database in the back office. Another source of input might be tiny radio-frequency identification (RFID) chips that are attached to patients and send basic information when they come in range of a radio field. Patients could also add inputs themselves. A firm called Health Hero, for instance, makes a cute little device called a Health Buddy that patients take home and plug into their telephone lines. A couple of times a day, it asks them basic questions or takes their heart rate, and sends the data to the doctor.

Behind the scenes, all this data would be formatted and stored according to recognised standards. Contrary to widespread concerns, this does not require a single central repository or any other particular hardware architecture. Instead, it relies on common software protocols and formats so that individual computer applications can find and talk to one another across the Internet. Most of these standards, such as XML, SOAP and WSDL, already exist and are used by many industries. Others, such as HL7, LOINC or NCPDP (spelling them out makes them sound no less obscure) are unique to the health-care industry and govern data interchange between hospitals, laboratories and pharmacies. On top of these, there need to be hacker-proof layers of authentication and password protection so that only the right people get access.

There is still some work to do to refine these technologies. In January, eight of the world's largest IT companies – Microsoft, Oracle, IBM, HP, Intel, Cisco, Accenture, and Computer Sciences – teamed up to form an 'interoperability consortium' for that very purpose. In general, however, "the technology is very, very ready," says Robert Suh, the technology boss at Accenture, a consultancy that is helping

Britain's National Health Service (NHS) and regional governments in Australia and Spain to implement electronic health records.

In fact, Britain's – or rather England's – NHS is among the pioneers worldwide. This year, it will begin rolling out a £6.2 billion (\$12 billion) project in which five regions in England will form networked IT 'clusters' so that 18,000 NHS sites, including all family doctors and acute-care hospitals, can share standardised information on patients. These clusters will eventually be linked through a 'spine' (called the N3 and run by the main UK telecoms provider, BT) with huge bandwidth to create, in effect, one national network. Scheduled to be completed by 2010, the plan, like most IT projects, has had some early hiccoughs and has been greeted with cynicism by some doctors. But other countries will be looking to it as a model.

Another pioneer is Denmark, which began rolling out a similar network for the region around Copenhagen in 2001 and expects to complete it by 2007, before covering the rest of Denmark. Torben Stentoft, the boss of Hvidovre Hospital in Copenhagen and the head of the city's network, says that his main concern is the nitty-gritty of dealing with all of his legacy computers which need to be tweaked or replaced. But he feels that he has his society's full support. "Nobody is against this. Everybody is asking for it," he says. In particular, the Danes find nothing terribly controversial in the idea of a national health identification number, which they already have, and spend little time worrying about how to fund the new systems, since their tax kroner are doing that.

AMERICAN EXCEPTIONALISM

Mr Stentoft is in an enviable situation, especially if viewed from America, which has the world's largest and costliest health-care system. America is as enthusiastic as any country about electronic health records. President George Bush has embraced the idea, and he spoke about it publicly some 50 times last year. He has even appointed a "national co-ordinator for health information technology" to create a fully interoperable, nationwide network within ten years. But America's health-care system is so

different from others that it faces some special complications.

The first big difference is that, whereas most other rich countries have 'single-payer' (i.e. government-run) health-care systems, America has a highly fragmented industry with many private providers and insurers doing business alongside large government programmes (such as Medicare, for old people). This means that in funding a new IT infrastructure "the financial incentives are not exactly aligned," says Mr Bates. In single-payer systems, the expenditures come out of the same pocket – the taxpayer's – that the savings go into. But in America, he estimates, the practices and hospitals that pay for the IT only get 11% of the cost savings, with the rest going to insurers and employers (who buy the insurance). The resulting mismatched incentives, says Mr Bates, could derail the entire project: "It's a situation where America could end up far behind."

This calls for some combination of government subsidies and private-sector financial incentives, argues the Markle Foundation, a charity in New York that is dedicated to the proper use of IT in health care and national security. Over half of all doctors in America work in small practices. And, say Markle's researchers, a typical practice (defined as five doctors handling 4,000 patient-visits a year) would make losses if it had to pay the estimated \$15,000 a year for three years that it costs to install an interoperable IT system and to learn how to use it.

The practices, Markle concludes, therefore need incentives of \$3 to \$6 per patient-visit, or \$12,000 to \$24,000 a year, which comes to \$7 billion to \$14 billion a year for three years, or between 1.2% and 2.4% of total ambulatory-care revenues. The trickier question is how to administer this largesse, whether it is provided by insurers and employers or the government. The money could be disbursed directly and specifically for the IT systems. Or it could be given indirectly in some sort of pay-for-performance arrangement.

The other big difference between America and countries such as Denmark is public perception of the robustness of privacy laws. The

Opinion polls in Europe show huge support for properly regulated interoperable medical databases

European Union has stricter privacy laws than America, and Europeans have relatively more confidence in them. For information sharing, “ours is a much more porous environment,” says Alan Westin, a professor at Columbia University who has written several books on privacy issues. This is not primarily an IT issue, although the Internet does seem to raise the stakes.

In February, one database broker, ChoicePoint, had to inform some 140,000 people that it had accidentally sold sensitive information about them. Also in February, a statistician of the health department in Palm Beach County, Florida, inadvertently e-mailed a list of more than 6,000 HIV carriers to all employees of the department.

This makes many Americans suspicious of plans that involve sharing sensitive health information. Although opinion polls in Europe show overwhelming support for interoperable medical databases as long as these are properly regulated, a February poll by Harris Interactive found that Americans are currently evenly split, with 48% saying that the benefits outweigh the privacy risks, and 47% saying the opposite. Some 70% of Americans in the poll worried that sensitive data (on sexually transmitted diseases, say) might leak.

This is unfortunate, says Michael Callahan, a health-care lawyer at Katten Muchin Zavis Rosenman, a law firm in Chicago, since a weighty tome of legislation was passed in 1996 precisely to prevent such leaks. Called HIPAA (short for “Health Insurance Portability and Accountability Act”), the law defines strict codes for sharing medical data and takes effect in stages. HIPAA creates a national ‘floor’, says Mr Callahan, with some states following even stricter statutes, and involves the federal govern-

ment in enforcement and prosecution. HIPAA is not quite as strong as equivalent laws in Europe, he thinks, but strong enough.

Mr Westin disagrees. The HIPAA rules are “not at all adequate” for shared medical records, he says. So the only way to sell such records to the American public, he says, is to design the whole system with privacy as a priority. This rules out any form of medical identification card, to which Americans would be hostile (even though they think little of giving their social-security numbers, a de facto ID, when renting DVDs). It also means avoiding a central database that could be hacked. The best approach, says Mr Westin, is to emulate the ‘locators’ used by American police. Cops in California who arrest a New Yorker cannot access information about that person directly, but can view a directory of such information and request it from the authorities in New York. Finally, rather than allowing sceptics to opt out of the new system, says Mr Westin, the system should from the start require patients actively to opt in.

As the Markle Foundation puts it, the technology must be designed in such a way that “decisions about linking and sharing are made at the edges of the network” by patients in consultation with their doctors, and never inside the network. This goes to the very heart of the matter. For even though it is fine to start hoping for the day when interoperable electronic health records create vast pools of medical information that could be used to find new cures and battle epidemics in real time, their ultimate purpose is to make one simple and shockingly overdue change: to enable individuals, at last, to have access to, and possession of, information about their own health.