The one certain consequence of the President’s allocation of new funds to NIH is the time we’ll all need to recover from the Recovery Act! Extrapolate the number of whirling dervishes at UF chasing deadlines for administrative supplements, competitive revisions, challenge grants, etc., etc. across the nation’s Academic Health Center landscape and there’s little wonder that NIH has been bracing for all sorts of IT calamities from the deluge of submissions.

Fortunately, the CTSI’s own IT prospects are becoming clearer and brighter every day. Under the expert leadership of Dr. Mike Conlon, Interim Director of our Biomedical Informatics (BMI) Program, critical core IT infrastructure is developing to support the Institute’s various programmatic activities and the research undertaken by its investigators and trainees. However, we are starting essentially from scratch, and getting where we want to be in BMI is a multi-year process with plenty of challenges en route. Nevertheless, as the following article by Mike and our colleague, Dr. Bill Yasnoff, points out, the rewards for all of us are worth the journey.

A final important reminder: Because of the (welcome) distraction of Recovery Act funding opportunities, we have extended the deadline for receipt of applications for the CTSI’s latest RFA for its Pilot and Collaborative Projects Program funding to 5 PM THIS THURSDAY, APRIL 30. Please send us your proposals formatted as directed in last month’s Newsletter and good luck!

Peter W. Stacpoole, PhD, MD
Director, General Clinical Research Center
Director Clinical and Translational Science Institute
Associate Dean Clinical Research and Training
Anyone who has ever seen more than one doctor or been to more than one medical clinic knows how difficult it can be to have information shared between them. Even when someone has been referred by another provider, it often becomes the patient’s responsibility to explain their problem, what was previously done to treat it and why he was referred for additional testing or care. He may be asked to produce his previous x-rays or lab results. And before being seen, the patient is typically required yet again to fill out a lengthy history asking him to recall the lifetime of medical and health ills he has faced, including all the many medications he is taking and surgeries he has had – things that can be tough to remember on the best day by even the most knowledgeable.

Multiply that scenario by more than 300 million people in the United States, hundreds of thousands of health providers, and more than a half million health care facilities and it provides a glimpse of the enormity and complexity of the task this nation faces in creating the comprehensive and fully electronic health record system being advocated by President Barack Obama and others. Proponents say such a system could substantially decrease health costs while improving quality of care, reducing medical errors, decreasing health disparities, and providing greater freedom and control for patients. The success of that challenge is dependent on cooperation and effort across a variety of spheres, with biomedical informatics at the forefront of those endeavors, including at UF and the CTSI.

The first question patients are typically asked by their health providers is, “What are you allergic to?” It’s a simple, routine question. But one that patients should not be answering because it allows is too much room for inaccurate recollection and errors that can result in overprescribing, drug interactions, increased costs, and serious repercussions including death, according to Dr. Michael Conlon, Ph.D., UF’s director of data infrastructure and interim director of biomedical informatics. The answer to that question – and many others – is one health providers should be able to obtain from a patient’s medical record, no matter who saw the patient previously, where, or how long ago, Conlon said.

But as things are now, that is usually not the case. “It’s impossible to know what’s in the medical records because they’re scattered all over the place,” Conlon said. And “the records are not shared.”

**Scattered records**

Patients usually have a primary care doctor. They may see specialists — often several — for conditions such as cancer, heart disease, or skin problems. They get their eyes checked by an ophthalmologist, and their contacts and glasses from an optometrist. They see a dentist to get their teeth fixed. They may go to a hospital for tests or procedures, or if they are in a car accident. They get their prescriptions filled at a pharmacy, and sometimes several different ones as they can get some drugs cheaper at certain places. If they have an allergic reaction to food on the weekend, they may go to a stand-alone clinic. All of these facilities and health providers have their own records, and rarely is information exchanged between them. As a result, virtually no one receives care today with the benefit of comprehensive medical records covering all their previous medical history.
Despite the computer revolution affecting most aspects of society, the medical establishment has been slow to adopt computerized documents, with an estimated 80 percent of health clinics still using paper records and filing systems, according to Conlon. That means information needed by a health provider seeing a patient for the first time is commonly not available, and even when it is, what’s accessible is often summaries that are incomplete, requiring patients to fill in the gaps. Although many are becoming significantly more involved in their health care, patients are not always the best at recollecting the detailed and complex health information that may be required, which can be further influenced by stress and illness. Complicating matters further is that high levels of education don’t necessarily correlate to health knowledge; the U.S. government has shown that even well-educated people having graduate-level master’s and doctoral degrees sometimes have low health literacy levels.

Electronic health records

Many believe the way to overcome some of these hurdles is through electronic medical or health records, also called EMRs or EHRs, and health record banking. Consumers have already shown significant interest in EMRs. In national surveys by global consulting and technology services company Accenture in 2005 and 2007, a slight majority of people said they would be willing to pay $5 or more a month for their records to be digitized, said Dr. William Yasnoff MD, PhD, a biomedical informatics consultant to UF and the CTSI. Some patients, especially those with chronic diseases and those who see a number of different providers, already routinely carry their paper records with them so their doctors have all the information they need, he said. Yasnoff, who is the managing partner of Alexandria, Va.-based NHII Advisors and spoke as part of the CTSI lecture series in November, has been intimately involved with several government health information technology initiatives. He worked with the Centers for Disease Control and Prevention, and as Senior Advisor for the National Health Information Infrastructure at the U.S. Department of Health and Human Services in Washington, D.C., where he organized and implemented the activities leading to the creation by President Bush of the Office of the National Coordinator for Health Information Technology in 2004.

The push for electronic health information continues and is being expanded by the new administration, and UF and Shands will be involved in efforts to develop and implement such systems, Conlon said. Transition to these systems, along with clinical and translational science endeavors aimed at significantly decreasing the amount of time it takes for proven improvements in health care to make their way into widespread community use are dependent on biomedical informatics, including those being undertaken at UF through the CTSI, according to Yasnoff.

More than 16 percent of U.S. gross domestic product (GDP) is spent on health care – about $2.2 trillion – with projections indicating that if these costs continue to grow at their current rate, they will rise to 25% of GDP by 2025, according to the U.S. Department of Health and Human Services. However, evidence suggests adopting EMR systems could significantly decrease those costs, which economists repeatedly point to as necessary to help repair the nation’s financial woes and ensure its future financial strength. In a 2001 report, the Institute of Medicine concluded that the use of information technology in health care, including through EMRs, could decrease U.S. health costs by 20 percent, which “could save many hundreds of billions
of dollars,” Conlon said. Beyond the medical cost savings, EMRs also would improve care. In part, this would be facilitated by a switch from the provider-centric medical record currently in place – focusing on the advice, treatment, medications, tests, etc. that each provider furnishes – to being a patient-centric record concentrating on the person’s health and illness and all that is associated with it, Conlon said.

Not everyone is sold on the idea that EMRs will save the nation money. But Yasnoff said focusing on cost savings misses the critical issue. Several organizations that have widely instituted the kinds of complete electronic health information systems being proposed for adoption nationally, have all seen costs go down and quality improved as a result. Some of these organizations include Kaiser Permanente headquartered in California, Group Health of Puget Sound, the Veterans Administration, and Harvard Pilgrim Health Care in New England. But more important according to Yasnoff is that these kinds of electronic systems provide more complete information on which policy decisions can be made and monitored almost in real time without the years of delay before their real impact is understood, as is now the case. “If we don’t have electronic records, there’s no chance we’re going to save money, there’s no chance we’re going to improve quality, and there’s no chance that we’re going to be able to make timely and reasonable health policy decisions because we just don’t have the information,” he said.

Discussion of digitizing health records is not new. The federal Health Insurance Portability and Accountability Act, or HIPAA, adopted in 1996, contemplated patients’ ability to carry their medical information with them when they moved from one job to another. However, its privacy provisions have garnered the most attention, Conlon said. At least until now.

**Health record banks**

Electronic records, with their accompanying ease of exchange and comprehensive patient-specific information, are not enough, according to Yasnoff. Also needed is a mechanism for aggregating all the records about each person and the arsenal of other relevant health information and delivering them to providers at the exact point when they must make medical decisions. Without this, health providers are making decisions without the complete knowledge and information they need, which he likens to airline pilots working without the backup we – and they – rely on. “The pilot may be very experienced and competent but everyone knows that human beings just do not function with 100% accuracy 100% of the time, and that’s why we have copilots and instruments and warnings in the cockpit,” he said. “In health care we don’t have that yet.”

The means for compiling and transferring the information to providers is the health record bank aspect of the initiative that would function similar to a bank account, said Yasnoff. After seeing a patient, a provider would deposit the new medical information from the visit into the patient’s health “account.” Only the patient would have the ability to authorize a provider to see any or all of the information in their account. Based on instructions from the patient, the health record bank would transfer to a provider only what it had been authorized to release. In this way, each person is able to “set their own personal, customized privacy policy,” he said.

EMRs alone are simply electronic silos of information just like the paper files kept currently by each different
health provider. But when you combine them with a health record bank that can store and transmit the information where it’s needed and when, it’s value “increases dramatically” to both providers and patients, he said. The nation’s first three health record banks became operational in March in three communities in Washington state, and other states and communities are in earlier stages of implementation.

**Numerous options**
The newest health information technology initiatives are supported from the highest levels of government down. However, developing truly interchangeable EMR systems is a mammoth task, and one that will take many years. As of now, proponents and those closest to the issue haven’t even determined the best of several possible ways for implementing it, Conlon said. “There’s a lot of thinking about how personal health records could happen.”

One possibility is a single database on which all a person’s records would be stored. Online medical storage systems of this type are currently commercially available through Microsoft HealthVault and Google Health, but these systems require partnerships with medical providers and permission by individuals for their doctors, clinics, hospitals and others to submit personal health information automatically over the Internet. Such systems must overcome tremendous logistical hurdles, as well safety and security issues, and privacy concerns, Conlon said.

Another possibility would involve a network of health information that would remain distributed among various providers, but would be shared when authorized by a patient, however fraud and other difficulties are a concern, according to Conlon. Health organizations like Shands are currently the most likely entities to have interchangeable records, but focusing future efforts on such institutional systems is problematic because of the complexities involved in their making records available to external providers. The U.S. Department of Veterans Affairs has an advanced and comprehensive system, Conlon said, yet it still has issues, including that it currently doesn’t interface with the Department of Defense medical records of military personnel.

Yasnoff believes the most viable option is for for-profit companies that are independent of any health other health organization to build health record banks in local geographic communities. A non-profit community organization consisting of local patients and providers would govern the record bank, which would also be regulated by the federal and/or state governments, and collaborate with a for-profit to develop and operate it. Consumers would have complete control over and access to their records.

**Consumer-controlled system**
This consumer-centric system is the most feasible alternative for several reasons, he said, including that most health care is provided on a local basis, and that the local community is where the public trust needed to support these banks has the best chance of developing. In addition, for-profit organizations are generally run more efficiently than non-profits and are better able to raise the capital that will be necessary for the technology and other infrastructure that will be needed.

*Continued on page 7*
At a clinical encounter, the clinician requests information from the health record bank about the patient. If the patient does not give permission for release of information, none is sent. Normally, patients would give permission so their electronic medical records are sent to the clinician. Care is given, and the encounter data is stored in the clinician’s Electronic Health Record (EHR) and then transmitted to the health record bank for use in subsequent encounters. Optionally, the physician can be paid a small fee for submitting the encounter data, thereby offsetting the cost of the EHR system.
The health record bank’s business model involves two costs, one to run the bank and the other to cover the cost of EMRs for providers, which together total an estimated $16 a year per person on average based on a million subscribers. Although the basic health record account would be free to consumers, revenue would be derived from various optional reminders and alerts to which people could subscribe for modest additional fees. Yasnoff estimates these fees would conservatively amount to about $12 a year per person. Non-intrusive ads similar to those found on Google would generate about another $6 a person per year, or people could opt out of the ads by paying those monies themselves. As a result, the expected per person revenue exceeds costs by $2 per person per year, which results in a profitable business, said Yasnoff, who describes these costs in detail on his blog at www.yasnoff.com.

Not only would no government funds be involved, but the model generates income without even taking into consideration any health care cost savings that may be realized, he said. The approach also protects patients’ privacy, ensures cooperation by the various stakeholders, is financially sustainable, and can ensure that all medical records in a community are electronic and available for providers and patients. “This is a business model that is totally self-sustainable based on new value that is delivered to consumers,” he said, “and that’s a huge advantage.”

Perhaps the closest thing currently available to an interchangeable record system is the so-called digital dog tag provided to American combat soldiers. Not only can these tags store their entire medical records on a microchip, but medics can use handheld devices to transfer medical information to the tags on the battlefield. The entered data is used in the immediate future by Department of Defense hospital providers caring for the wounded soldiers, but also becomes a permanent part of their electronic DOD health records. The government is making an effort to further integrate medical records for members of the U.S. military into a comprehensive system that will contain their lifetime of medical information starting from the day they enlist. In early April, President Obama announced that the DOD and VA were moving for the first time toward creating a unified electronic health record for members of the U.S. armed forces.

Although controversial for privacy reasons, health-related microchips for civilians have also been developed, with the Food and Drug Administration giving approval for the first such under-the-skin chip in late 2004. However, unlike their military counterparts, these chips the size of a rice grain don’t actually contain health information, instead they transmit an identification number that identifies a person and provides access to medical information stored in an associated database.

Despite all the possibilities and the accompanying uncertainties, one thing is guaranteed with respect to EMRs: No matter the system, ethical and legal issues will proliferate. For example, agreement about exactly what someone has authorized to have released will always be sticky. “There’s nothing straight-forward about this,” Conlon said.

Government funding
The government seems to understand that, and has committed significant funding to support these efforts nationwide, money that UF and Shands will seek to aid in the significant challenge they face in integrating their own records, which include several disparate
information systems. The UF faculty physicians group has one system, Shands Gainesville another, with a separate one for Shands Jacksonville, and some other Shands facilities having different systems still.

The U.S. Office of the National Coordinator for Health Information Technology, whose budget skyrocketed from $61 million to $26 billion under the new administration, will distribute $28 billion for various initiatives from the American Recovery and Reinvestment Act of 2009. Among the act’s goals is that each person in the U.S. will have an electronic health record by 2014. Enhancements to help safeguard personal health information will be ongoing as well, and as required by the Act, the U.S. Department of Health and Human Services released guidelines April 17 aimed at improving the security of this data and preventing harm that can be caused if it is breeched.

The largest pot of those stimulus monies – $19 billion – will be used for incentives to Medicare and Medicaid providers to adopt systems that allow interchangeable medical records that meet federal standards, Conlon said. The earlier they do this, the larger the payouts they will be eligible for, and as time goes on the incentives decline. Five years after the program begins, those who care for these government-insured patients – which include most providers – will be penalized for not having implemented such systems. Standards have not yet been established, but UF and Shands already are examining ways to develop a coordinated system that will adhere to any new government criteria, Conlon said.

Another $7 billion will be used to provide the improved infrastructure and high-speed networks necessary for providers to have the capacity to exchange medical information. UF and Shands could use some of these monies to hook up some outlying areas or clinics and improve connections to Jacksonville, but overall “we have very good network infrastructure,” Conlon said.

The last pot of $2 billion will be used to facilitate development of innovative health record systems and health care delivery technologies through multidisciplinary research centers at universities and other institutions of higher education. The goal will be to obtain funding to establish one at UF, Conlon said.

The latest initiatives are only beginning and face numerous obstacles nationwide. However, the Biomedical Informatics program at UF and the CTSI should help ease the transition. “Medical records are very complicated, and we’re trying to figure out how to get it all together,” Conlon said. “It’s a challenge within our own institution.”

That raises the question of how successful the recent – and expensive – health information technology initiative is likely to be, especially given such limited adoption in the past. Yasnoff thinks the probability is good for two main reasons, and he thinks there’s a good chance it will happen before the 2014 deadline date. First, technology has improved so these kinds of systems are now possible. More important is that is has become a national priority, and with that has come funding to support the effort.

“Given the fact that there’s now a model that solves all these problems, and people are starting to implement this approach around the country, I don’t think it will be long before the dream of comprehensive health records for everybody at any point of care becomes reality,” he said.
MEET THE BMI LEADERS

Michael Conlon, PhD, is the Associate Chief Information Officer for IT Architecture and Director of Biomedical Informatics in the UF College of Medicine. His responsibilities include development of academic biomedical informatics, expansion and integration of research and clinical information resources as well as strategic planning for university information resources. Previously Conlon served as PeopleSoft Implementation Officer and Chief Information Officer of the UF Health Science Center where he directed network and video services, desktop support, media and graphics, application development, teaching support, strategic planning and distance learning.

He earned his doctoral degree in statistics from UF, and undergraduate degrees in mathematics and economics from Bucknell University. He is the author of more than 150 scholarly publications and presentations. His current interests include enterprise change and organizational issues in the adoption of information technology, large scale data systems integration, enterprise architecture, and computing administration.

William A. Yasnoff, MD, PhD, is a well-known national leader in health informatics and the founder and managing partner of National Health Information Infrastructure (NHII) Advisors, and the founder and president of the Health Record Banking Alliance. He also is an adjunct professor of Biomedical Informatics at UF. In recognition of his pioneering contributions to the field of public health informatics and the development of the nation’s health information infrastructure, he was awarded an honorary DrPH by the University of Louisville in May 2006.

Previously, Yasnoff served as senior advisor, National Health Information Infrastructure (NHII) for the U.S. Department of Health and Human Services. Beginning in late 2002, he initiated, organized, and developed the HHS activities directed at promoting and encouraging the NHII, which led to the presidential creation of the Office of the National Coordinator for Health Information Technology, establishing NHII as a widely recognized goal for the nation. Before coming to the Washington, D.C. area, Yasnoff worked for the CDC as associate director for science, Public Health Practice Program Office, and for the Oregon Health Division, where he developed and deployed a statewide immunization registry that is still operating successfully today and an electronic information network for public health officials. Yasnoff also spent many years in the private sector, and did consulting work for a variety of commercial, academic, and government clients, addressing a wide range of health informatics challenges.

In addition to his UF affiliation, Yasnoff, who received both his doctorate in computer science and M.D. from Northwestern University, is an adjunct professor of Health Sciences Informatics at Johns Hopkins, a professor (gratis) of Health Management and Systems Sciences at the University of Louisville, and an adjunct professor of Biomedical Informatics at the University of Illinois in Chicago. He co-edited the textbook “Public Health Informatics and Information Systems,” and has authored more than 300 scientific publications and presentations.
Employment

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- [http://www.sfa.ufl.edu/programs/ops.html](http://www.sfa.ufl.edu/programs/ops.html) - Other Personnel Services jobs.
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