CLOUD
Consortium for Local Ownership and Use of Data, Inc.

A New Contextual Language to Improve the Usefulness of Immunization and Vaccination Records

Are immunizations just a health issue?

Our health information necessarily crosses data boundaries. The immunization record, critical as each new school year gets underway, is a timely example of how data silos contain our information and constrain efficient, private, and secure use of use information to protect personal and public health. The H1N1 virus is the latest example of why it's important to know exactly when and where vaccines are delivered successfully and when and how particular diseases are causing illness. CLOUD could make this part of the world of medicine a better place to live.

Before CLOUD

The process of meeting school immunization requirements today can be inefficient – or, in most cases, completely inefficient. In Texas, if you're organized, you have immunization cards listing required shots for each child. You grab the cards from your paper files and make copies for each child's school. The schools then assign staff to manually input student information into tracking and compliance systems.

That's the best case scenario. But if you don't remember where one of those cards is filed or if your child hasn't had the necessary shots, it's off to the pediatrician's office to start piecing together the information. And this assumes your family hasn't moved or changed pediatricians while the various immunizations have been delivered, in which case the necessary shot records are even more scattered. In any case, self-reported personal health records – the latest trend – don't meet state, agency, and school immunization requirements. Properly authenticated vaccination documents are required; doctors' credentials and official medical records still matter.

From a public health perspective, the consequences of vaccination regimens are vital. We vaccinate

to limit the spread of diseases like polio, hepatitis, rubella, and small pox that ravaged children several decades ago. H1N1 may not be as serious, but it's an important test to prepare for more deadly influenza viruses in the future. Speed and effectiveness of vaccination are both vital, particularly to populations most at risk. In the world of HIPAA, privacy rules make data silos even tougher to navigate, hampering speed and effectiveness.

This example highlights the number of 'touch points' in our daily healthcare 'transactions.' The school immunization workflow and process is one way information from our health domain affects our daily lives and our children's health. Immunization touch points extend far beyond doctors' offices, yet the routine of managing these various touch points has numbed us to the insanity of clinging to manual processes in the post-industrial era. As we traverse basic services, there are large numbers of 'touches' from start to finish, the vast majority of them inefficient when measured against modern data handling capabilities. Merely consider the number of times you are handed a clipboard to transfer or capture information, and one begins to understand the breadth of the problem.

What is CLOUD?

CLOUD is an approach that starts with a change in perspective. In the world of immunizations and vaccinations, there is one constant among all of the touch points, ranging from local school districts to clinical researchers studying diseases and vaccinations: YOU!

Touch points

The challenge is that YOU exist in a large number of different places. Using manual processes to reconcile these touch points wastes inordinate amounts of time and challenges every provider in the information value chain. Doctors, insurance companies, school districts, state education agencies, and health care providers are all burdened, not by activities in their core competencies, but by the reality of having to move data.

Because these touch points exist in their own data silos, reconciling this information requires a whole lot of moving: moving from the paper on the clipboards into the data systems at the doctor or school; moving the digital bits from the doctor to the insurance company; moving data from you to your

doctor; moving the data from the insurance company to you; moving the data from you to the school; moving data from the school to state agencies. And these are just a few places your data needs to move.

Standards and the Real Problem

Standards to move this data around are in place. In the case of health care, there is HL7 (Health Level 7). In schools, there is SIF (Student Interchange Framework). While YOU may be in both of these data silos, the silos can't connect because the standards don't connect. If the standards did what they are supposed to do, then YOU wouldn't be moving all this data around.

If, however, data and context are aligned around YOU, some of these data problems begin to evaporate. You only have a problem syncing data if you are… well…trying to sync data! Of course, you don't need to sync YOU, because, well, YOU are always you.

If there were a new contextual markup language for people – not just for data and messaging protocols – then the one constant in this whole data equation makes every other part easier, for you and for those you allow to use your information.

Your name, address and other pertinent personal information rarely change, and when they do, they change for most or all purposes. So in the modern world of education and health records, why must this information exist in at least two places: school student information system and doctor's office? The fact that it exists in those places and many others leads to waste and inefficiency. It also involuntarily subjects data owners – individuals – to privacy rules designed to constrain the activity of data users, such as insurance companies and schools: HIPAA (http://en.wikipedia.org/wiki/HIPPA) in the case of healthcare and FERPA (http://en.wikipedia.org/wiki/FERPA) in the case of education.

Privacy through Individual Control of YOU

Of course, privacy problems evaporate if you are in firm control of your own identity and personal information. Privacy and security challenges exist because security breaches with respect to school records, insurance records, or doctors' records can compromise both your data and your identity. CLOUD breaks this cycle by taking advantage of the capabilities of electronic systems to simply work better than physical world clipboards.

So if it is all about YOU, you become the glue that brings together these different parts of the CLOUD. At the same time, all participants in the value chain save the costs of privacy compliance, since you are back in control of your identity and its tethers.

These are really your immunization records, right? They may be stored in systems run by the doctor (paper or electronic), but nonetheless, they are still yours. The best place for them to remain is with the doctor, but with the standards envisioned by CLOUD, data can be reconnected by you whenever you need it. No more moving data around; just tag particular data like a Flickr photo or a YouTube video to set the privacy level, and everyone who needs it can see it, publicly or anonymously. And no one can see it without your permission.

Other Benefits of a CLOUD-Enabled Internet

The implications of the CLOUD-enabled approach are significant for individuals and institutions alike. Pediatricians could store information securely and save the time and costs of HIPAA compliance. The extra time could translate into an extra patient visit each day, meaning an additional 20 patients a month, or more time to spend with existing patients – better care, more capacity and more revenues, instead of more costs. For clinicians and researchers, the ability to observe an anonymous mosaic of reliable health information and track the success of drugs, devices, and other treatments is difficult or impossible in today's world of HIPAA and data silos. CLOUD could change that.

Electronic health records alone do relatively little without changes in the business process to use those records more efficiently. As the Department of Health and Human Services implements EHR rules from the Feb. 2009 stimulus bill and vendors pursue certification to tap into billions of dollars of funding, this work will simply move data problems from paper filing cabinets to digital filing cabinets – unless we change the paradigm to empower data owners to control their personal filing cabinets. That is CLOUD's promise.

After CLOUD

With this in mind, let us return to the immunization story in the CLOUD world – and the potential of improving the experiences of patients, providers, schools, and everyone to whom public health is important.

The most visible outcome of a CLOUD-enabled world for immunizations is the elimination of the immunization card itself. Whether online or off, the standard behind CLOUD – ME 1.0 – makes visible, at the patient's direction, any information people want to share. From the point of immunization forward, the locus moves to the individual. When the doctor or nurse administers the shot, rather than a series of clipboards and scraps of paper, the experience is more direct and dynamic. When you arrive at the receptionist, simply swipe a CLOUD-enabled magnetic card or present your CLOUD-enabled cell phone and enter your PIN. When the immunizations are delivered, they automatically become part of your pediatrician's business process for billing purposes and are tagged and CLOUD-enabled for your purposes.

When you log in to your Web-based CLOUD provider of choice, you can review your health records in multiple formats – not merely in the fixed format of a proprietary electronic health record. You can tag your immunization records, fully accessible to you and privately accessible to those whom you give access. In this case, the tag you associate with your immunization record may be that of your local school district.

For the school district, CLOUD streamlines workflow and decimates compliance costs. No longer must the school manually receive every immunization card. School officials need only look at an anonymous mosaic of incoming students to ensure 100% immunization coverage. Rather than tracking every record, they need only look at who lacks a current immunization record tagged to the school.

Known as "white listing" among Internet technologists, this process makes data handling vastly easier and less expensive. The school simply directs a confidential[?] message to parents who have not tagged a child's immunization record for the school's use. Once the records are complete and the tag applied, the flag flips and compliance is achieved. If the messages are ignored, the student does not

appear on class lists posted prior to the start of school and during the annual registrations and round-ups, motivating positive, rather than negative compliance. Even better, the school need no longer spend valuable education dollars on yet another upgrade to their student information system to track health records already tracked in the health sector. Information is collected and managed once because the individual lives at the center of the information eco-system.

Assuming each transaction or touch of an immunization requires 10 minutes (five minutes of school time and five minutes of parent time), then a school district of 10,000 requires around 1600 labor hours to complete this task or over 40 people with an average 40 hour work week. This doesn't include the aggregate impact of the data on the front end at the pediatrician's office. And this is one school district of 10,000 kids. Houston Independent School District has over 100,000 students. It adds up.

From the health provider's perspective, a CLOUD-enabled world is equally compelling. Simplifying the patient check-in process is not only streamlined for the immunization itself, but the cost of presenting, reading, and inputting non-medical data from a clipboard during every visit is eliminated.

Connecting information through CLOUD could help pediatricians as it helps schools. Perhaps one more patient a day, five a week, 20 a month, 240 in a year? Better, faster, and less expensive information for medical professionals means practices that are more profitable, healthier patients, and better services for their communities.

Patient-provided ME tagging would also yield the opportunity to create an infrastructure to support dramatically more efficient interactive on-line health interviews. Today, when patients write down symptoms, behavior, and activities on clipboards for medical professionals to review, the clipboard is incapable of asking relevant follow-up questions. Putting the health interview on-line promises to make it more comprehensive and more detailed, giving the professional more time and information to zero in on concerns when meeting with the patient.

The world after CLOUD is different. It requires ME and YOU to work together to redefine the way in which we exist on the Internet. The implications are powerful with respect to immunizations and extend to clinical trials and other aspects of healthcare, along with education, financial services, and myriad other economic and social activities. Join us for the ME revolution!