

Date: January 11, 2010

To: Shawn Doherty, Health Reporter  
The Capital Times

From: Fred Buhr, MSSW  
Metasteward LLC

Re: The little state that could - but didn't!

As you pointed out in your 2009 year in review article, it's certainly been quite a year for health care and Wisconsin health officials have done many things right. When it comes to innovative programs to cover the uninsured, I am proud that Wisconsin has cemented a national reputation for being the "Little State That Could". But, I am saddened to say that Wisconsin is the "little state that could - but didn't" when it comes to eHealth privacy and security.

By virtue of failing to institute "[Fair Information Practices](#)" in all Department of Health Services (DHS) organizational units years ago, Wisconsin, in my opinion, now is the weakest link of all the states in electronic health records (EHRs) networks.

Last week, the Centers for Medicare and Medicaid Services (CMS) and the Office of the National Coordinator for Health Information Technology (ONC) published two rules. The first proposed interim rule was titled "[Initial Set of Standards, Implementation Specifications, and Certification Criteria for Electronic Health Record Technology](#)". The second was a notice of proposed rulemaking related to "[Medicare and Medicaid Programs Electronic Health Record Incentive Program](#)". [Taken both together](#), they provide guidance relating to "meaningful use" requirements with which providers will have to comply in order to gain bonuses under the American Recovery and Reinvestment Act of 2009 (ARRA).

[An article in January 4's Healthcare It News](#) said that physicians and privacy advocates aren't pleased with the "meaningful use" requirements, but for far different reasons. Deborah Peel, M.D., a psychiatrist who is founder and chairwoman of Patient Privacy Rights, said the rule "does not contain the single most important criteria American patients and consumers demand to trust electronic health systems: control over personal health information." She went on to say the rule "guarantees that the stimulus billions will be wasted to purchase obsolete, unethical EHR 'clunkers' instead of EHRs with privacy-enhancing technologies that put patients in control of their sensitive health records, from prescriptions to DNA.

Based upon my experience with the electronic health records system mandated by Wisconsin to be used by all Older American Act programs, I whole heartedly agree with Dr. Peel. My comments at the end of the article are titled "[Dr. Peel is Right](#)." Wisconsin's implementation of the Social Assistance Management System (SAMS) is the

most privacy invasive and least secure of any system in the country and portends disaster for Wisconsin's efforts to develop [Health Information Exchanges \(HIEs\)](#).

In August 2009, Wisconsin released a request for information ([RFI Long-term Care Managed Care Infrastructure Project](#)) with the intent to use the information developing a request for proposal (RFP) in 2010 for infrastructure software to together all state and local systems. The RFI is long and complex but can visually be summarized by looking at [Appendix F](#)

The effect of the project will be to "grandfather" the Social Assistance Management System (SAMS) which the State mandates for use by all Area Agencies on Aging (AAA), senior centers and senior outreach programs. The crux of my concerns is that SAMS as implemented by Wisconsin blatantly ignores the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and other federal and state laws relating to privacy and security of systems. Harmony Inc. on its website implies that agencies can achieve HIPAA-compliant security for all databases in their networks by using [AgingNetwork.com](#) as the Web-host for SAMS.

One of the forms used by Dane County is called: DETERMINE (attached). Because the form lacks Dane County identification a person is unable to be sure that it is a legitimate form authorized for use by Dane County. The reason for the lack of Dane County identification is that the materials have been adapted, apparently without permission, from the 1988 Nutrition Screening Initiative (NSI) project. Sponsors of NSI included: the American Academy of Family Physicians (AAFP), the American Dietetic Association (ADA) and the National Council on the Aging, Inc (NCoA). The project was funded in part by a grant from Ross Laboratories, a division of Abbott Laboratories.

The original version of the form can be found at: <http://tiny.cc/F0I2L> . The materials from the Nutrition Screening Initiative were intended to be educational in nature and be purchased in quantities from the project, not copied and used to collect individually identifiable personal health information (PHI) to be stored in a database. In fact, the screening checklist is noted in several studies as never having been validated for use with the elderly.

One study reported in the July 1997 issue of the Journal of the American Dietetic Association indicated the DETERMINE tool should not be used by dietitians and caregivers as a screening tool for nutritional risk in the elderly. The study written by four researchers from the Human Research Center on Aging at Tufts University said that because the individual questions of the checklist identify specific targeted problems that may have long term impact, they may be missed if the cumulative score is used as the sole criterion for screening people. The researchers said that if the individual risk factors were taken separately and their consequences eliminated, premature death might be avoided in nearly 20 percent of the men and 51 percent of the women in the original survey. An abstract of the study can be found at: <http://tiny.cc/30qK5>

The statement at the bottom of the form indicating that, "The information you are being asked to provide is needed to determine if you are eligible to receive Older Americans Act Services and to comply with federal reporting requirements," is simply not true. Not a single one of the questions relates to eligibility for either the congregate or home delivered meals program and the mandate to use the form was issued by the Nutrition Checklist Committee composed of members from Dane, Washington, Barron, Waukesha, Waushara, Eau Claire counties and BADR staff. Most importantly individuals are not made fully aware that a permanent SAMS' electronic health record (EHR) is established when they complete the registration and assessment forms.

Wisconsin is the only state to configure SAMS so as to display individuals' most sensitive information in "user fields" on the summary screen (copy attached). Information can be directly entered and edited from the summary screen and since "user fields" are not regular data base fields, no audit trail is created or maintained. Entries in the "user fields" can be made by any person with access to an individual's record and information from other databases or data warehouses can be entered without a person's knowledge or approval.

Among the most sensitive "user fields" available for entry are those related to mental health diagnoses. The group of five diagnostic fields, shown on the attached summary screen likely relate to the multi axial system of the Diagnostic and Statistical Manual of Mental Disorders (DSM). The mental health module in the Human Services Reporting System (HSRS) and associated fields in the MEDS data warehouse organizes each psychiatric diagnosis into five levels (axes) relating to different aspects of disorder or disability. A definition can be found at: <http://tiny.cc/x3JZ5>

I recognize the five diagnostic fields being included in the MEDS data warehouse from my work on data quality related to the Mental Health Data Infrastructure Grant (DIG) in 2002. Concern during that period was expressed by counties as shown in minutes from a 2003 meeting of the Wisconsin Council on Mental Health: <http://tiny.cc/nbP7T> . Additional "user fields" provide drop downs for various diagnoses including the one for depression that I've shown on the attached summary screen. The linkages between physical and mental health is explored in the Behavioral Risk Factor Survey: <http://tiny.cc/nyo9J>

When a data entry operator enters information for a new participant, the SAMS application executes a broad search that brings back a listing of all participants, from communities across the state, having similar sounding names. The summary screens from all matching records, with the most sensitive information plainly visible, can be viewed without actually opening records by any one with access rights to the SAMS system. There does not appear to be an audit trail relating to who views records. Concerns expressed in 2003 by the Wisconsin Council on Mental Health appear to have been well founded

Currently the State Data Infrastructure Coordinating Center (SDICC) is discussing participation of states' mental health units in health information exchanges (HIEs) being

developed by states under the Health Information Technology for Economic and Clinical Health (HITECH) Act. HITECH was enacted as part of the American Recovery and Reinvestment Act (ARRA) of 2009 commonly referred to as the Stimulus Bill. A summary of the October 2009 SDICC regional calls can be found at: <http://tiny.cc/k8nRV>

In addition to my volunteer work for the McFarland Senior Outreach Program, I am a volunteer member of the [U.S. Health Information Technology Standards Panel](#) (HITSP) and serve as a volunteer on several technical committees and workgroups. I am a member of the HITSP Consumers Preferences Tiger Team (CP-TT) that directly provides comments to the Office of the National Coordinator for Health Information Technology (ONC).

In order to give Dane County residents greater confidence in the privacy and security of our health information, I suggest that Dane County consider commissioning a security and privacy risk assessment of the information programs of the Dane County Area Agency on Aging. I believe that my privacy rights and those of all others who participate in the congregate and home delivered meals programs have been violated and that our personal health information is stored in databases having security vulnerabilities.

On November 3, 2009 I attended the meeting of the Wisconsin Council on Long Term Care and expressed my concerns relating to the privacy and security of SAMS electronic health records of the elderly. A summary of my comments is included in the preliminary November minutes at <http://tiny.cc/24rUF>. My written presentation can be seen on my website at: <http://www.metasteward.net/2009.htm>.

Tomorrow, January 12, 2010 I plan to attend the meeting of [Dane County's Long Term Support Committee](#) and offer similar comments during the "Open Forum" agenda item using the "Determine" form and "SummaryScreen" that I've attached above.

Recently the U.S. Department of Health and Human Services issued an interim final rule that strengthens enforcement and increases penalties for violations of the Act. Prior to HITECH the penalty could be no more than \$100 for each violation or \$25,000 for all identical violations of the same provision. Section 13410(d) of the HITECH Act strengthened the enforcement by establishing tier ranges of increasing minimum penalty amounts, with a maximum penalty of \$1.5 million for all violations of an identical provision. The strengthened penalty will encourage healthcare entities to comply with HIPAA requirements. The [interim final rule \(IFR\)](#) was effective November 30, 2009 although it remained available for public comment until December 29, 2009.