

Comments to eHealth Wired Board – August 20, 2010

Good morning, I am Fred Buhr, data entry operator for the McFarland (Wisconsin) Outreach Program. I am one of 8,500 dues paying members of the American Civil Liberties Union (ACLU) of Wisconsin, one of 125,000 elderly and disabled Older American Act participants in Wisconsin, one of 50,000,000 Social Security and Medicare recipients in the U. S., one of 69,000,000 individuals throughout the nation afflicted by multiple chronic conditions (MCCs) and founder of Metasteward LLC

My company's name "Metasteward" is a contraction of the words "metadata" and "steward" and descriptive of the continuation (as an independent researcher) of my work begun in the Department of Health and Family Services (DHFS). From 1998 until 2005 (when the unit was dissolved) I was a member of the Center for Uniformity, Security and Privacy (CUSP). During the early part of that period I was the principal staff person supporting the "Data Stewardship Council" and development of the "DHFS Common Core Data Standards".

The definitional work of the DHFS Council was modeled on that of the United States Health Information Knowledgebase (USHIK) utilizing a beta version of a distributable metadata registry. The DHFS project was the only one of its kind in the nation following American National Standards Institute (ANSI) and International Standards Organization (ISO) standards.

USHIK is housed and funded by the Agency for Healthcare Research and Quality (AHRQ) and contains all data elements and products accepted by the Health Information Technology Standards Panel (HITSP). The use of USHIK tools is critical to establishing a semantic infrastructure will enable health information exchange (HIE) at all levels.

I began my volunteer job entering data for the McFarland Senior Outreach program in August 2007 and immediately felt that the system had design flaws that violated my rights to privacy and security of my health information. In April 2008, I sent a letter to Secretary Timberlake and Secretary Morgan (Department of Administration) describing my concerns and requesting that the eHealth Care Quality and Patient Safety Board consider recommending a law that would prohibit state or local agencies from circumventing ADMIN12, HIPAA and state privacy and open meetings laws through their placing the electronic records in data centers outside the state of Wisconsin.

I have documented my efforts to seek corrective action concerning the Social Assistance Management System (SAMS) on my website at: <http://www.metasteward.net>. SAMS is software as a service (SaaS) hosted on Harmony Inc.'s proprietary website: <http://www/agingnetwork.com>. Although McFarland is a focal point agency of the Dane County Area Agency on Aging, Dane County itself does not have a direct relationship with Harmony. Rather, the business relationship with Harmony is managed by the Bureau of Aging and Disability Resources (BADR) in the Wisconsin Department of Health Services (DHS) and the Greater Wisconsin Agency on Aging Resources, Inc. (GWAAR).

I believe the attachments (combined with the data entry screens) clearly show why I am so deeply concerned. The chronic disease self-management program (CDSMP), originally developed by the Stanford University School of Medicine, began in Wisconsin in 2004 and is one of the most outstanding programs in country, but the questionnaires should be kept private and medical conditions should not be listed on the electronic SAMS records kept on individuals. This year, Wisconsin received allocations under the federal American Recovery and Reinvestment Act of 2009 (ARRA) to support activities related to CDSMP.

ARRA, or the Stimulus Bill as it is known, dramatically strengthened privacy regulations related to medical information. Under the privacy provisions of ARRA, the Attorneys General of the States, can, if they have reason to believe that an interest of one or more of the residents of the State has been or is threatened or adversely affected by a violation of a provision, as *parens patriae* may bring a civil action on behalf of such residents of the State in a district court of the United States of appropriate jurisdiction.

Because I believe that the Bureau of Aging and Disability Resources (BADR) and the Greater Wisconsin Area Agencies on Aging (GWAAR) are violating the privacy and security of my personal health information and that of other Older Americans Act participants, I intend to file a complaint with Wisconsin's Attorney General requesting that he intervene in his ARRA defined role as *parens patriae*.

The Warning Signs of poor nutritional health are often overlooked. Use this checklist to find out if you are at nutritional risk.

DETERMINE YOUR NUTRITIONAL HEALTH

Read the statements below. Circle the number in the yes column for those that apply to you. For each yes answer, score the number in the box. Total your nutritional score.

		YES
Q1 01	I have an illness or condition that made me change the kind and/or amount of food I eat.	2
Q1 02	I eat fewer than 2 meals per day.	3
Q1 03	I eat few fruits or vegetables, or milk products.	2
Q1 04	I have 3 or more drinks of beer, liquor or wine almost every day.	2
Q1 05	I have tooth or mouth problems that make it hard for me to eat.	2
Q1 06	I don't always have enough money to buy the food I need.	4
Q1 07	I eat alone most of the time.	1
Q1 08	I take 3 or more different prescribed or over-the-counter drugs a day.	1
Q1 09	Without wanting to, I have lost or gained 10 pounds in the last 6 months.	2
Q1 10	I am not always physically able to shop, cook, and/or feed myself.	2
	TOTAL	

Total Your Nutritional Score. If it's –

0–2 Good! Recheck your nutritional score in 6 months.

3–5 You are at moderate nutritional risk. See what can be done to improve your eating habits and lifestyle. Your office on aging, senior nutrition program, senior citizens center or health department can help. Recheck your nutritional score in 3 months.

6 or more You are at high nutritional risk. Bring this checklist the next time you see your doctor, dietitian or other qualified health or social service professional. Talk with them about any problems you may have. Ask for help to improve your nutritional health.

Remember that warning signs suggest risk, but do not represent diagnosis of any condition. Turn the page to learn more about the Warning Signs of poor nutritional health.

These materials have been adapted from the Nutrition Screening Initiative, a project of American Academy of Family Physicians, The American Dietetic Association and National Council on the Aging, Inc.

The Nutritional Screening Initiative, 2626 Pennsylvania Avenue, NW Suite 301, Washington, DC 20037. The Nutrition Screening Initiative is funded in part by a grant from Ross Laboratories, a division of Abbott Laboratories.

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. This information will be stored in a secure electronic database and will not be used for any other purpose. Your information will not be shared with another agency without your permission. This information will not be sold to anyone. You have the right to review your electronic record and request changes to assure accuracy. You will not be denied most services if you refuse to provide information. If you have questions regarding this, please ask the aging unit staff.

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- Billing
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H. (Not Indicated) (Not Indicated)

Primary Care Manager: (Not Assigned)

[\(Edit Notes\)](#)

Personal	Characteristics	Insurance
Social Sec. No.	Language English	Medicaid #
Date of Birth Unknown	Homebound No	Medicaid Policy#
Age Unknown	Frail No	Medicare #
Status: Active Status Date: 08/17/2010	Disabled No	Medical Assistance ID
AKA Name	Is Abused/ Neglected/ Exploited No	User Fields (Add New)
Maiden Name	NAPIS	qi01(+2)-Illness changed food? Don't Know (Edit)
Info Release? No	Ethnicity Unknown	qi02(+3)-Fewer than 2 meals? Don't Know (Edit)
Date Registered 08/17/2010	Is In Poverty Don't Know	qi03(+2)-Few fruits/veg/milk? Don't Know (Edit)
Details Last Reviewed 08/17/2010	Lives Alone Don't Know	qi04(+2)-Three or more drinks? Don't Know (Edit)
Marital Status Unknown	High Nutritional Risk Don't Know	qi05(+2)-Hard to eat? Don't Know (Edit)
Gender	Is Rural Don't Know	qi06(+4)-Not enough money? Don't Know (Edit)
County Not Indicated	Number of ADLs Not Assessed	qi07(+1)-Usually eats alone? Don't Know (Edit)
Municipality Not Indicated	Number of IADLs Not Assessed	qi08(+1)-Three or more drugs? Don't Know (Edit)
Primary Phone Number Not Indicated	Current Providers (Add New)	qi09(+2)-Gained/Lost 10+ lbs? Don't Know (Edit)
Current Contacts (Add New)	Current Caregivers (Add New)	qi10(+2)-Can't shop/cook/feed? Don't Know (Edit)
Current Care Enrollments (Add New)		qi92-Initial Assessment Score 0 (Edit)
03-Title III (Active) 08/17/2010 - None (Edit)		qx99-Nutrition Notes (Edit)
Current Service Suspensions (Add New)		Routes (Add New)
Activities & Referrals (Add New)		Current Care (Add New)

Information Sheet about Evaluation of Living Well with Chronic Conditions

Title of the Project: Evaluation of Living Well with Chronic Conditions

Evaluation Director: Jane Mahoney, MD (phone: 608-262-8597), University of Wisconsin Medical School, 2870 University Ave., Suite 106, Madison, WI 53705

The State of Wisconsin Dept of Health and Family Services and the University of Wisconsin Medical School and are doing a program evaluation of Living Well with Chronic Conditions to see how well it helps people stay healthy. You are invited to participate in this evaluation by completing 2 questionnaires. The questionnaires ask you about your health and how you are feeling. You will complete one questionnaire now, and one questionnaire 6 months after your classes end. Each questionnaire will take about 20 minutes.

Your participation in the questionnaires is voluntary. If you decide not to do the questionnaires, you will still receive the full Living Well with Chronic Conditions program. There is no benefit to you from completing the questionnaires, but it may help us learn more about how to make these programs successful. You will not be paid for answering the questionnaires.

We will do all we can to keep your questionnaires private. The information from the questionnaire will be put in a database, but the database will only identify your questionnaire by a number and will not have your name or other information to identify you. Your name and contact information and the number you were assigned will be kept in a locked file in the evaluation director's office at the University of Wisconsin-Madison for 6 months after your last questionnaire, then destroyed.

You can decide to stop the questionnaire at any time or skip any questions you want.

The information you are being asked to provide is needed to comply with federal reporting requirements. This information will be stored in a secure electronic database. Your information will only be used for program information and will only be shared with those agencies doing the evaluation. Your information will not be sold to anyone. You have the right to review your electronic record and request changes to assure accuracy. If you have questions regarding this, please ask the agency staff.

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H. (Not Indicated) (Not Indicated)
 Primary Care Manager: (Not Assigned)

(Edit Notes)

<p>Personal</p> <p>Social Sec. No.</p> <p>Date of Birth: Unknown</p> <p>Age: Unknown</p> <p>Status: Active Status Date: 08/16/2010</p> <p>AKA Name</p> <p>Maiden Name</p> <p>Info Release?: No</p> <p>Date Registered: 08/16/2010</p> <p>Details Last Reviewed: 08/16/2010</p> <p>Marital Status: Unknown</p> <p>Gender</p> <p>County: Not Indicated</p> <p>Municipality: Not Indicated</p> <p>Primary Phone Number: Not Indicated</p> <p>(Add New)</p>	<p>Characteristics</p> <p>Language: English</p> <p>Homebound: No</p> <p>Frail: No</p> <p>Disabled: No</p> <p>Is Abused/ Neglected/ Exploited: No</p> <p>NAPIS</p> <p>Ethnicity: Unknown</p> <p>Is In Poverty: Don't Know</p> <p>Lives Alone: Don't Know</p> <p>High Nutritional Risk: Don't Know</p> <p>Is Rural: Don't Know</p> <p>Number of ADLs: Not Assessed</p> <p>Number of IADLs: Not Assessed</p> <p>(Add New)</p>	<p>Insurance</p> <p>Medicaid #</p> <p>Medicaid Policy #</p> <p>Medicare #</p> <p>Medical Assistance ID</p> <p>(Add New)</p> <p>User Fields (Add New)</p> <p>Routes (Add New)</p> <p>Current Care Recipients (Add New)</p>
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Current Contacts [\(Add New\)](#)

Current Care Enrollments [\(Add New\)](#)

03-Title III (Active) [\(Edit\)](#)

08/16/2010 - None

Current Service Suspensions [\(Add New\)](#)

Activities & Referrals [\(Add New\)](#)

Last Assessments [\(Add New\)](#)

Current Care Management [\(Add New\)](#)

Add User Field

Details

User Field:

Prompt: **lw1-Diabetes**

- lw2-HeartDisease
- lw3-Hypertension
- lw4-LungDisease
- lw5-Depression
- lw6-ArthritisRheum
- lw7-Cancer
- lw8-OtherChronic

OK Cancel

Social Assistance Management System



Run-time error '-2147217900':

Incorrect syntax near the keyword 'AND'.

Close

System Info...

Details >>

Save As Copy Print Collapse All Expand All

Errors

- SstErrorHandling
 - Version = 1.1.0
 - EXENAME = SstErrorHandling
 - Path = C:\Program Files\Common Files\Synergy Software Technologies
 - ProcessID = 512
 - ThreadID = 3924
 - MachineName = SQL04B
- frmServiceRosterSuper2
 - FilePrintToolClick
 - Error1
 - DateTime = 8/15/2010 1:46:12 PM
 - Severity = 3
 - Number = -2147217900
 - Description = Incorrect syntax near the keyword 'AND'.
 - Source = frmServiceRosterSuper2.FilePrintToolClick