

Testimony: Wisconsin Council on Long Term Care
September 7, 2010

Good morning Chair Bruemmer and Members of the Council.

My name is Fred Buhr. I am a volunteer data entry operator for the McFarland (Wisconsin) Senior Outreach Program.

I am also a member of the U.S. Health Information Technology Standards Panel (HITSP) and over the years have served on many workgroups of that panel. This past year, I participated on the Consumer Preferences Tiger Team which reported directly to the Office of the National Coordinator (ONC) for Health Information Technology. The consumer preferences team provided advice relating to technical specifications for implementing consumer preferences in future health information technology.

I am currently a member of the Health Level Seven (HL7) Personal Health Records (PHR) workgroup which is a subcommittee of the HL7 Electronic Health Records (EHR) workgroup. HL7 is an international standards development organization (SDO) that currently is working toward health information standards that will be implemented five or ten (or more) years in the future. When I was the in-house data consultant in the Center for Uniformity, Security and Privacy (CUSP) in the Department of Health Services (DHS) from 1998 to 2005, I served as DHS's public sector representative to HL7.

The following comment is not from a technical standpoint of future technology but rather from my point of view as a patient/consumer, today. My personally identifiable health data is stored in multiple systems maintained by many entities, including but not limited to: U.W. Health, Meriter, Dental Health Associates, Wisconsin Physicians Services (WPS), and the Greater Wisconsin Agency on Aging Resources (GWAAR). GWAAR operates a system in collaboration with the Bureau of Aging and Disability Resources (BADR).

During a roundtable discussion on health care reform reported in the August 2010 issue of *Greater Madison InBusiness* magazine, Nino Amato, President and Executive Director of the Coalition of Wisconsin Aging Groups (CWAG) said, "The key is to take HIPAA off and begin to modify that law as an experiment, and get a waiver so all three hospitals begin to have that information." I totally disagree and point to the disregard of HIPAA by Wisconsin's nonprofits and the faulty security provisions of BADR and GWAAR as potentially permitting systemic fraud over the Internet that could account for billions of dollars of fraudulent payments related to medical identity theft.

BADR is Wisconsin's federally recognized state unit on aging (SUA) and is located in the Department of Health Services (DHS). GWAAR is a nonprofit association representing area agencies on aging (AAA) in 70 counties and 11 tribes. Although Dane and Milwaukee counties have independent area agencies on aging, they, along with the others, are required by BADR to utilize the Social Assistance Management System (SAMS). SAMS is a proprietary web-based application hosted on AgingNetwork.com owned by Harmony Information Systems of Reston, Virginia.

I believe that BADR and GWAAR are illegally operating Harmony's system of applications (including SAMS and Beacon) that co-mingle clinical and eligibility data of Home and Community Based Waivers (HCBW) program participants with clinical and eligibility data of Older American Act participants. SAMS and Beacon are the core information systems for Aging and Disability Resource Centers (ADRCs), Managed Care Organizations (MCOs) and Family Care (FC) providers. Database fields relating to the Community Integration Program (CIP), Community Options Program (COP), multiple chronic conditions (MCCs) and psychiatric diagnoses are utilized to track individuals' participation in programs.

I further believe that the Wisconsin Institute for Healthy Aging (a BADR/GWAAR nonprofit spin-off) bypasses Institutional Review Board (IRB) protocols and deceptively utilizes SAMS to collect and store individuals' health information by using misleading statements. A form containing a sentence such as: "The information you are being asked to provide is needed to comply with federal reporting requirements," does not, in my opinion, meet requirements of informed consent.

The SAMS system is most widely used solution in the United States for Home and Community Based Services (HCBS) Medicaid Waiver management and the Administration on Aging's (AoA's) National Aging Program Information System (NAPIS). AgingNetwork.com likely is the largest repository of individually identifiable protected health information (PHI) in the world. That information, if de-identified, represents the largest privately owned researchable database on the aging process in existence.

I believe the attachments 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 medical conditions of those participating in the Living Well with Chronic Conditions program 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 included dramatically strengthened HIPAA privacy provisions and included enabling language that allows the Attorneys General of the States to bring civil actions on behalf of State's residents directly into federal court.

Because I believe that the Bureau of Aging and Disability Resources (BADR), the Greater Wisconsin Area Agencies on Aging (GWAAR), the University of Wisconsin Medical School, the Wisconsin Institute for Healthy Aging, the Coalition of Wisconsin Aging Groups (CWAG) and Wisconsin's business associated nonprofits 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* - father of the people.

Thank you.

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.

This publication was made possible by Grant Number 90AM3111/01 from the Administration on Aging. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the US Dept. of Health and Human Services, Administration on Aging.

Accessed on 8/17/2010: <http://www.gwaar.org/images/stories/HealthPromotion/LWdatacollection/information-sheet-about-evaluation-of-living-well-with-chronic-conditions.doc>

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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>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>Insurance</p> <p>Medicaid #</p> <p>Medicaid Policy #</p> <p>Medicare #</p> <p>Medical Assistance ID</p> <p>User Fields (Add New)</p> <p>Routes (Add New)</p> <p>Current Care Recipients (Add New)</p>
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Current Providers [\(Add New\)](#)

Add User Field

Details

User Field	<input type="text"/>	OK
Prompt	<ul style="list-style-type: none"> lw1-Diabetes lw2-HeartDisease lw3-Hypertension lw4-LungDisease lw5-Depression lw6-ArthritisRheum lw7-Cancer lw8-OtherChronic 	Cancel

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

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