

Date: March 4, 2009

To: Dr. Robert Kolodner  
National Coordinator for  
Health Information Technology  
Department of Health and Human Services

Gary Cantrell, Director  
Computer Forensics and Investigative Research  
Office of the Inspector General  
Department of Health and Human Services

Pam Dixon  
World Privacy Forum

From: Fred Buhr  
President & CEO  
Metasteward LLC  
and  
Volunteer Data Entry Operator  
McFarland (Wisconsin) Senior Outreach Program

Re: Is the Social Assistance Management System (SAMS) a Health Information Technology (HIT) Engine for Medical Identity Theft?

Since August 2007, I have volunteered to be the data entry operator for the McFarland (Wisconsin) Senior Outreach Program. During my tenure as a volunteer, I have observed, documented, and reported to the Wisconsin Department of Health Services (DHS), the Wisconsin Department of Administration (DOA), the Wisconsin State Unit on Aging (SUA), the Dane County Area Agency on Aging (AAA), the Administration on Aging (AoA) and Harmony Inc.(the vendor) that the Social Assistance Management System (SAMS) and Agingnetwork.com have systemic privacy and security vulnerabilities.

To draw attention to my concerns, at one point I suspended my data entry activities but resumed, after three months, since my request for a risk assessment of the system had been dismissed by all parties. My efforts at the local and state levels to draw attention to the privacy issues for seniors and to the potential for medical identity theft on a truly breathtaking scale have met with failure due to local and state administrators' belief that Agingnetwork.com and Harmony Inc.'s applications (inclusive of any and all data elements) are not only endorsed by the Administration on Aging but that individuals' personal health data are collected and stored in an electronic database to comply with federal reporting requirements.

Similar to the federal government, Wisconsin has laws relating to privacy and requirements regarding records containing personally identifiable information. State and local agency administrators believe that electronic records entered into the SAMS system are not subject to state laws because the information is only reported in aggregate to the Administration on Aging through the National Aging Program Information System – State Reporting Tool (NAPIS SRT). On the AoA side, the National Aging Program Information System (NAPIS) is not regarded as being subject to the federal Privacy Act because only aggregate data is reported and no personal information is associated with the system. It is the lack of an identifiable governmental agency responsible for the protection of a vast number of personal health records of seniors and disabled citizens that prompts my question: "Are Agingnetwork.com and the Social Assistance Management System (SAMS) information technology (IT) engines of medical identity theft?"

In January 2008, I asked for a citation of the specific authority for requesting seniors to complete the form below. Even though Wisconsin has specific laws relating to the collection of personally identifiable information, I have only received the answer, as printed on the form, that it is “to comply with federal reporting requirements”.

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

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.

# DETERMINE YOUR NUTRITIONAL HEALTH

		YES
QI 01	I have an illness or condition that made me change the kind and/or amount of food I eat.	2
QI 02	I eat fewer than 2 meals per day.	3
QI 03	I eat few fruits or vegetables, or milk products.	2
QI 04	I have 3 or more drinks of beer, liquor or wine almost every day.	2
QI 05	I have tooth or mouth problems that make it hard for me to eat.	2
QI 06	I don't always have enough money to buy the food I need.	4
QI 07	I eat alone most of the time.	1
QI 08	I take 3 or more different prescribed or over-the-counter drugs a day.	1
QI 09	Without wanting to, I have lost or gained 10 pounds in the last 6 months.	2
QI 010	I am not always physically able to shop, cook, and/or feed myself.	2
	<b>TOTAL</b>	

## 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

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 refused to provide this information. If you have questions regarding this, please call the Area Agency on Aging of Dane County at 261-9700.

Answers to the questions are entered as “Yes” or “No” answers in “User Fields” and appear on the summary screen of individuals’ records, as shown in the demo case below.

Social Assistance Management System - [McFarland (Training Case Only), Millie - Consumer]

File Edit View Tools Window Help

Dashboard Consumers Activities & Referrals Rosters Routes Reports

Consumers McFarland (Training Case Only), Millie - Consumer

Close Consumer Save Save and Close Status Wizard

McFarland (Training Case Only), Millie 704281234 07/04/1928 80

**McFarland (Training Case Only),** **5915 Milwaukee Street**  
**Millie (704281234)** H. (608) 838-7117 **McFarland, WI 53558**  
 AREA AGENCY ON AGING OF DANE COUNTY Primary Care Manager: (Not Assigned)

(Edit Notes)

Personal	Characteristics	Insurance
Social Sec. No. 000-00-1234	Language English	Medicaid #
Date of Birth 07/04/1928	Homebound No	Medicaid Policy #
Age 80	Frail No	Medicare #
Status: Active Status Date: 05/01/2008	Disabled No	Medical Assistance ID
AKA Name	Is Abused/Neglected No	
Maiden Name	<b>NAPIS</b>	<b>User Fields</b> (Add New)
Info Release? No	Ethnicity Not Hispanic or Latino	qi05(+2)-Hard to eat? Don't Know (Edit)
Date Registered 05/01/2008	Lives Alone Don't Know	qi04(+2)-Three or more drinks? Don't Know (Edit)
Details Last Reviewed 05/01/2008	High Nutritional Risk Don't Know	qi01(+2)-Illness changed food? Don't Know (Edit)
Marital Status Unknown	Is Rural Yes	qi02(+3)-Fewer than 2 meals? Don't Know (Edit)
Gender Female	Number of ADLs Not Assessed	qi03(+2)-Few fruits/veg/milk? Don't Know (Edit)
County Dane	Number of IADLs Not Assessed	qi06(+4)-Not enough money? Don't Know (Edit)
Municipality Not Indicated	<b>Current Providers</b> (Add New)	qi09(+2)-Gained/Lost 10+ lbs? Don't Know (Edit)
<b>Current Contacts</b> (Add New)	McFarland Senior Outreach (05/01/2008 - None) (Edit)	qi92-Initial Assessment Score 0 (Edit)
<b>Current Care Enrollments</b> (Add New)	<b>Current Caregivers</b> (Add New)	qi10(+2)-Can't shop/cook/feed? Don't Know (Edit)
03-Title III (Active) 05/01/2008 - None (Edit)		qi08(+1)-Three or more drugs? Don't Know (Edit)
<b>Current Service Suspensions</b> (Add New)		<b>Routes</b> (Add New)
<b>Activities &amp; Referrals</b> (Add New)		<b>Current Care Recipients</b> (Add New)

MCFARLAND1 SAMS2K\_WI\_STATE 2/28/2009 8:17 PM

AgingNetwork.com is Harmony, Inc.’s proprietary Web-hosted network for accessing its suite of aging-services applications – including the Social Assistance Management System (SAMS).

AgingNetwork.com is accurately described by the company as the most widely used solution in the United States for Medicaid waivers management and creating reports for the Older American’s Act National Aging Program Information System (NAPIS). It provides a single-point-of-entry for all long term care data. Connectivity between individual applications in the Harmony suite is provided by data mining algorithms that are transparent to users. Harmony’s applications are licensed to agencies as a software-as-a-service (SaaS) and come with templates for entering data over the Web into databases physically located in Virginia and Vermont.

Fields included in the templates include identifying information for individual consumers, their caregivers, as well as their physicians and emergency contacts. The following chart shows the relationship between data elements included in the SAMS and Omnia applications.

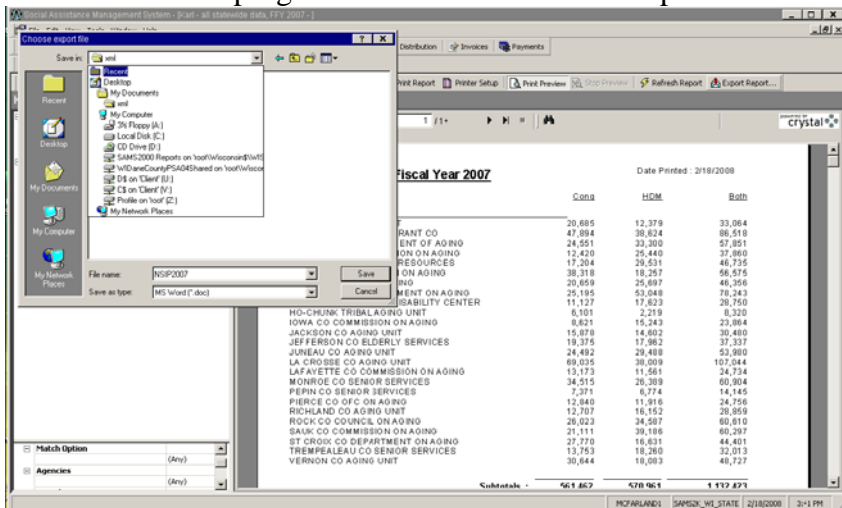
SAMS Field Name	Omnia Question ID	Omnia Question Name	SAMS → Omnia	Omnia → SAMS	Notes
Prefix	3948	Client name prefix	✓	✓	
First Name	1128	Client first name	✓	✓	
MI	1129	Client middle initial	✓	✓	
Last Name	1127	Client last name	✓	✓	
Suffix	1407	Client name suffix	✓	✓	
Birth Date	1134	Date of birth	✓	✓	
Age	1496	Age	✓	N/A	Calculated from DOB
SSN	1131	Social security number	✓		
Gender	1133	Gender	✓	✓	
Marital Status	1010	Marital status	✓	✓	SAMS choices only
In Poverty	2115	In poverty	✓	✓	
Is Rural	2117	Lives in rural area	✓	✓	
Ethnicity	4005	Ethnicity (Client)	✓	✓	
Lives Alone	1012	Living Arrangement	Requires Mapping	✓	
Consumer – language	1017	Primary Language	✓	Requires Mapping	
AKA Name	1493	AKA first name	✓	✓	Enter first, middle and last name on one line in SAMS
	1494	AKA middle initial	✓	✓	
	1492	AKA last name	✓	✓	
Directions to Home	1505	Directions to home	✓	✓	
Ethnic Race	4006	Race	Requires Mapping	Requires Mapping	
Nationality	4144	Nationality	Requires Mapping	Requires Mapping	
Home Phone Area Code	1495	Primary telephone	✓	✓	Must enter 10 digits
Home Phone Number					
Home Phone Extension					
Residential Address Street 1	1501	Residential address - Street/P.O. Box	✓	Requires Mapping	
Residential Address Street 2	4512	Residential address – street address line 2		Requires Mapping	
Residential Address Town	1502	Residential address - City/Town	✓	Requires Mapping	
Residential Address County	1724	Residential address - county	✓	Requires Mapping	
Residential Address State	1408	Client state of residence	✓	Requires Mapping	

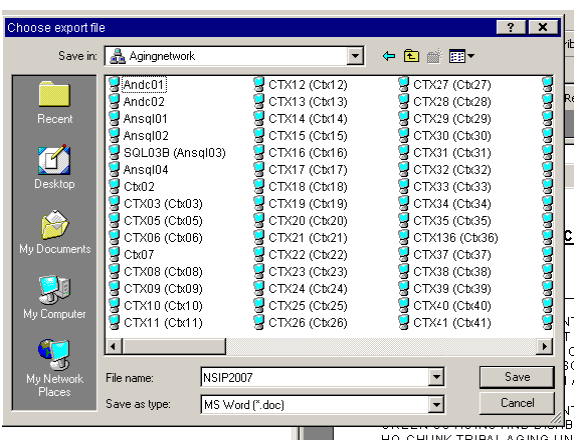
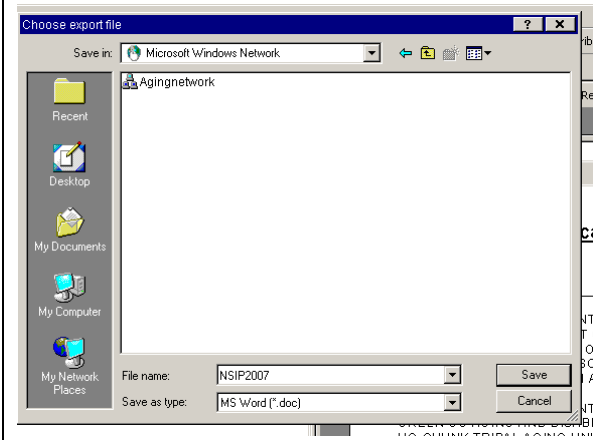
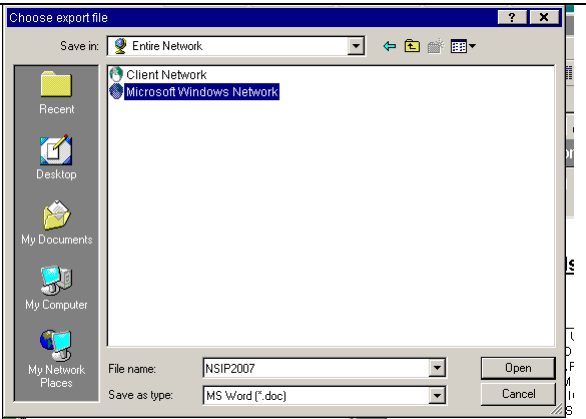
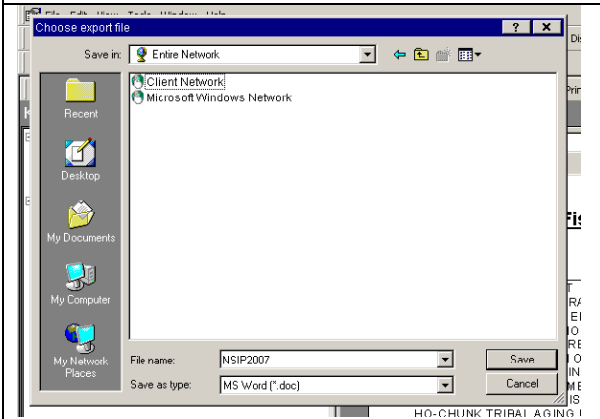
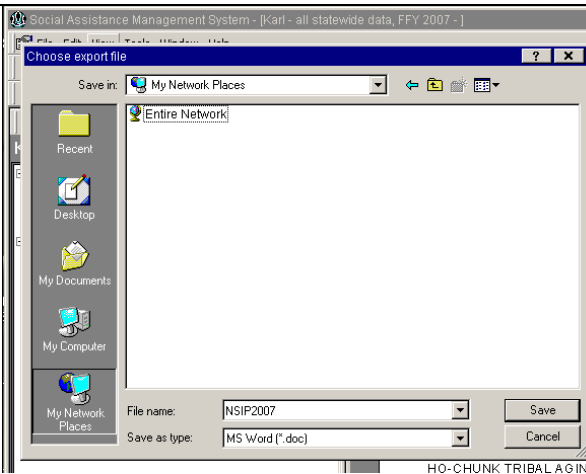
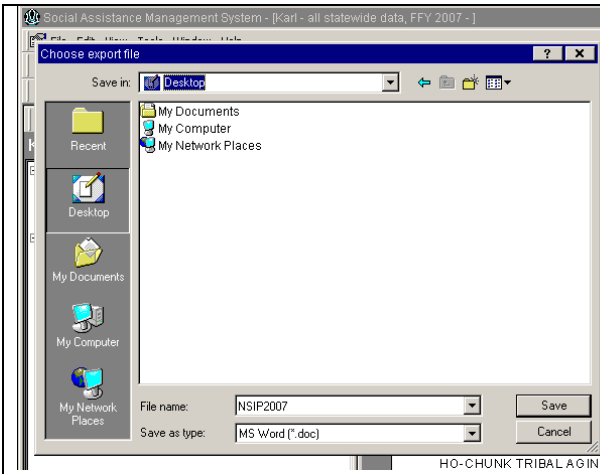
Residential Address ZIP Code	1409	Client zip code	✓	Requires Mapping	
Mailing Address Street 1	1497	Mailing address - Street/P.O. Box	✓	Requires Mapping	
Mailing Address Street 2	3750	Mailing address - Street address second line.	✓	Requires Mapping	
Mailing Address - Town	1498	Mailing address - City/Town	✓	Requires Mapping	
Mailing Address County	1715	Mailing address - county	✓	Requires Mapping	
Mailing Address State	1499	Mailing address - State	✓	Requires Mapping	
Mailing Address ZIP Code	1500	Mailing address - ZIP Code	✓	Requires Mapping	
Emergency Contact Name	2400	Emergency Contact - Name of Friend to contact.	✓	✓	
Emergency Contact Relationship	2401	Emergency Contact - Rel of Friend to contact.	✓	✓	
Emergency Contact Business Area Code	2403	Emergency Contact - Work tel. of Friend to contact.	✓	✓	
Emergency Contact Business Number					
Emergency Contact Business Extension					
Emergency Contact Home Phone Area Code	2402	Emergency Contact -Home Tel. of Friend to contact.	✓	✓	
Emergency Contact Home Phone Number					
Emergency Contact Home Phone Extension					
Emergency Contact - Residence Street 1	3510	Emergency Contact Address	✓	Requires Mapping	
Emergency Contact - Residence Street 2				Requires Mapping	
Emergency Contact - Residence Town	4635	Emergency Contact city/town	✓	Requires Mapping	
Emergency Contact - Residence County	4638	Emergency Contact county	✓	Requires Mapping	
Emergency Contact - Residence State	4636	Emergency Contact state	✓	Requires Mapping	
Emergency Contact - Residence Zip Code	4637	Emergency Contact ZIP code	✓	Requires Mapping	
Primary Physician Name	1025	Primary Doctor Name	✓	✓	

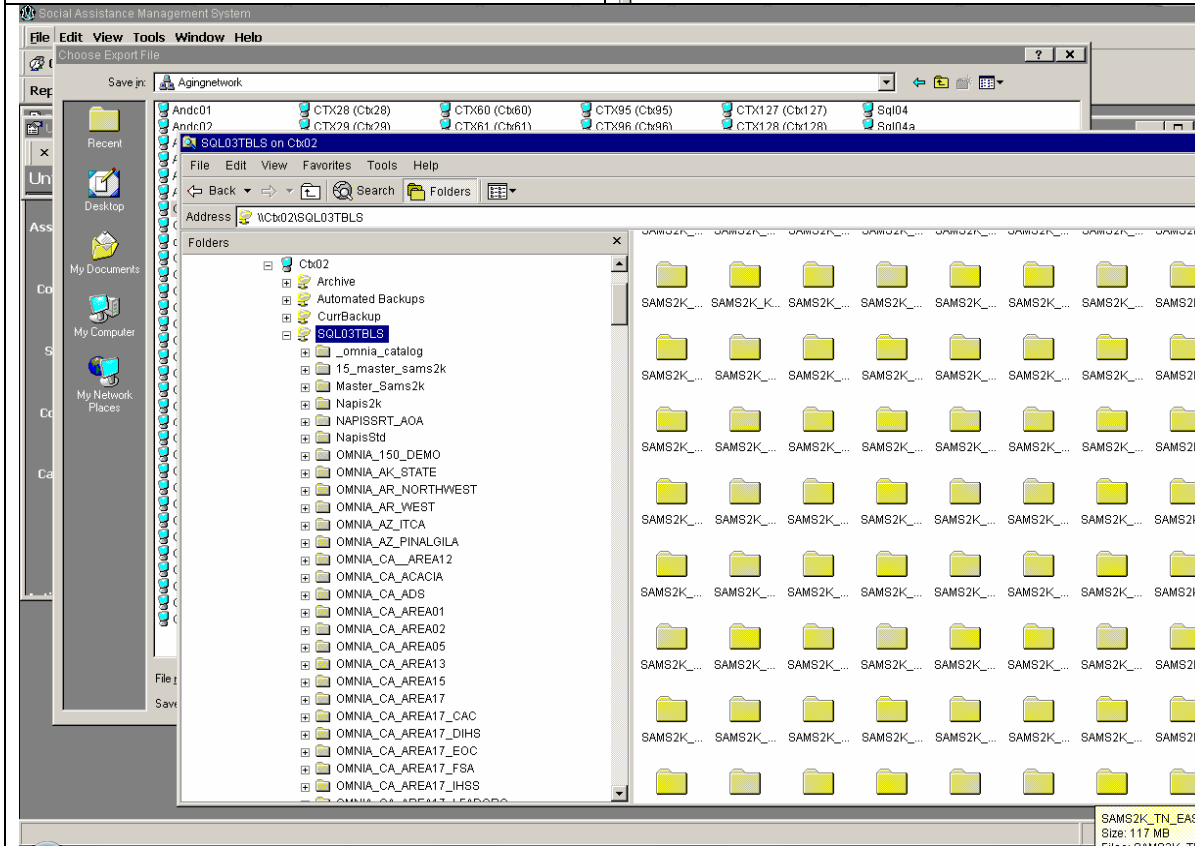
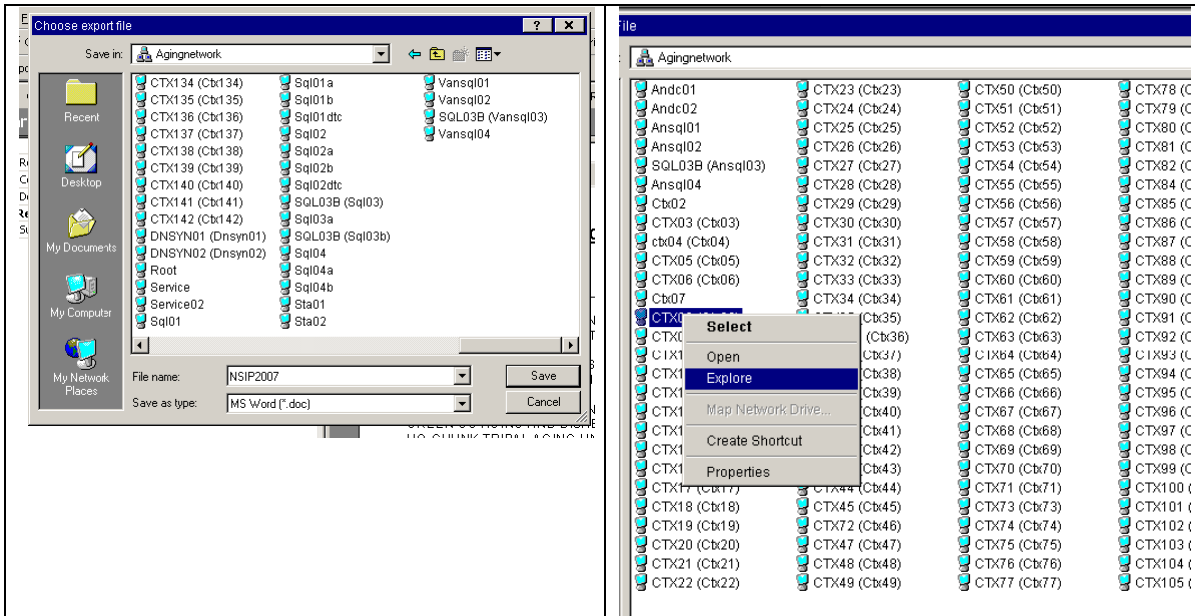
Primary Physician Business Area Code	1028	Primary doctor work phone	✓	✓	
Primary Physician Business Number					
Primary Physician Business Phone					
Primary Physician Home Phone Area Code	1027	Primary doctor home phone	✓	✓	
Primary Physician Home Phone Number					
Primary Physician Home Phone Extension					
Primary Physician Business Address Street 1	1026	Primary doctor Address	✓	Requires Mapping	
Primary Physician Business Address Street 2				Requires Mapping	
Primary Physician Business Address Town	4631	Primary doctor city/town	✓	Requires Mapping	
Primary Physician Business Address County	4634	Primary doctor county	✓	Requires Mapping	
Primary Physician Business Address State	4632	Primary doctor state	✓	Requires Mapping	
Primary Physician Business Address ZIP Code	4633	Primary doctor ZIP code	✓	Requires Mapping	
Number of ADLs	2118	ADL count or total	✓	**	
Number of IADLs	2119	IADL count or total	✓	**	
High Nutritional Risk	2116	High nutritional risk	✓	**	

\*\*Linked via built-in indicator = transferred to SAMS client record if all applicable questions are answered in the assessment form

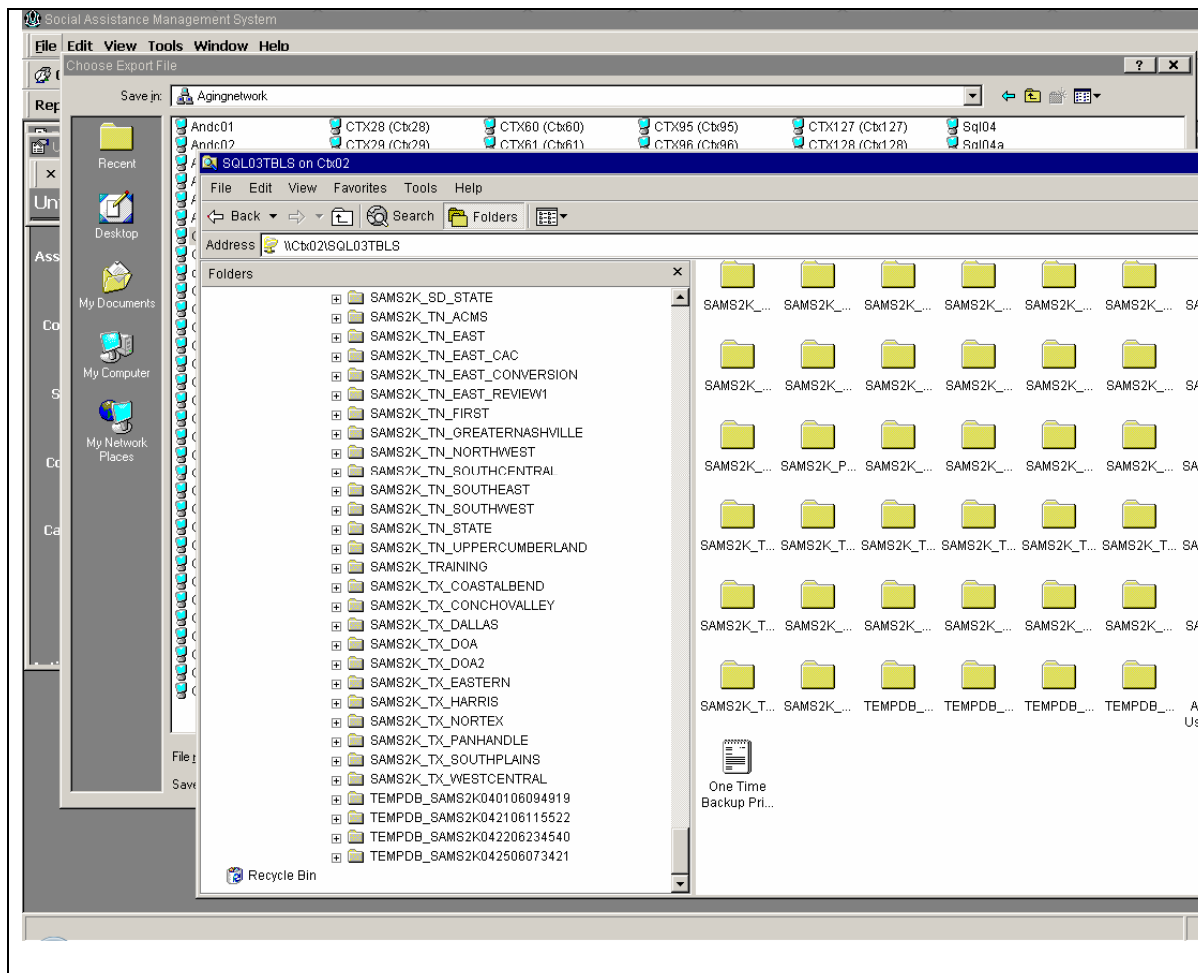
Since I have documented my concerns along with my correspondence on my Website, [www.metasteward.net](http://www.metasteward.net), I am attaching only a few screen prints showing security vulnerabilities - which I believed I had discovered but - which were already known to the agencies and to the vendor. Although the most observable vulnerabilities might have been corrected, I believe that a risk assessment of, not only what might have occurred before the vulnerabilities were corrected, but what still might be occurring because of design flaws, is warranted. The following screen prints were made when I inadvertently accessed the host program directories when I attempted to save and print a report in Word.







I believe that the Omnia SQL tables shown in the portion of the directory above are related to the SAMS2K SQL tables shown in the bottom part of the directory shown below. My recollection is that there were over 400 SQL tables shown in this directory.



During the Medical Identity Theft Town Hall meeting on October 15, 2008, Pam Dixon said that unless there is something very specific done to mitigate fraud within the system, health IT can actually be an engine for medical identity theft. She went on to speak about mitigation strategies, such as palm vein scans, which prevent one-offs but can be “a fantastic treasure trove for the folks that would steal identities because now you get some nice biometrics to steal, too.”

SAMS is an information system that provides a treasure trove of helpful information as it contains not only personal identity information but the names of physicians, care givers and detailed assessments of an individual’s health risks, activities of daily living (ADLS) and instrumental activities of daily living (IADLS). The system is well intentioned but presents a fantastic treasure trove for folks who would steal identities because the system is nation-wide in scope and accessible over the Internet – from any point in the world.

When I first encountered these screens in February 2008, I immediately sent an email to the Dane County and State of Wisconsin Social Assistance Management System (SAMS) administrators citing my concerns and urging that security officers be immediately contacted. My expectation was that the situation posed such a serious threat that both Governor Doyle and former Governor Thompson (who is on Harmony Inc.’s board of directors) would be notified and that the system would quietly be taken off line until the problems were corrected.

Because that did not happen, I pursued my concerns by meeting with DHFS security staff. I used the above screen shot to illustrate that icons representing SQL tables could be moved to the Recycle Bin and

they would be deleted. DHFS security officers were not impressed that constituted a security risk and rather focused on the question as to whether I had opened the files, which I had not. From that point on, all my concerns have been dismissed with assertions that there have not been any documented privacy or security breaches. In April 2008, I sent an open records request (with copies to the Associated Press and the ACLU) to the secretaries of the Wisconsin Departments of Administration (DOA) and Health and Family Services (DHFS) requesting:

1. Copy of current contract with Harmony, Inc for the Social Assistance Management System (SAMS)
2. Copies of agendas and minutes of the Nutrition Committee from year 2006 to present
3. Copies of the agendas and minutes of the Data Stewardship Committee for year 2000 and a listing of meetings for years 2001 to present
4. A report on the number of nutrition participants' records contained in Wisconsin's SAMS servers

Following passage of the Health Insurance Portability and Accountability Act (HIPAA) of 1996, the Department of Health and Family Services (DHFS) went through a period of intensive study of the law and all aspects of federal regulations as they were developed. I focused on the health identifier for individuals and studied descriptions of the proposals (from various sources) for unique personal identifiers. The set of descriptions was prepared by the National Committee on Vital and Health Statistics. Closely following the proposal developed by the University of California, San Francisco, Family Outcomes Project (FHOP), DHFS internally established a set of core data elements which were to serve to identify any individual recorded in DHFS record keeping systems and a data stewardship program was established for data sharing, privacy and security issues.

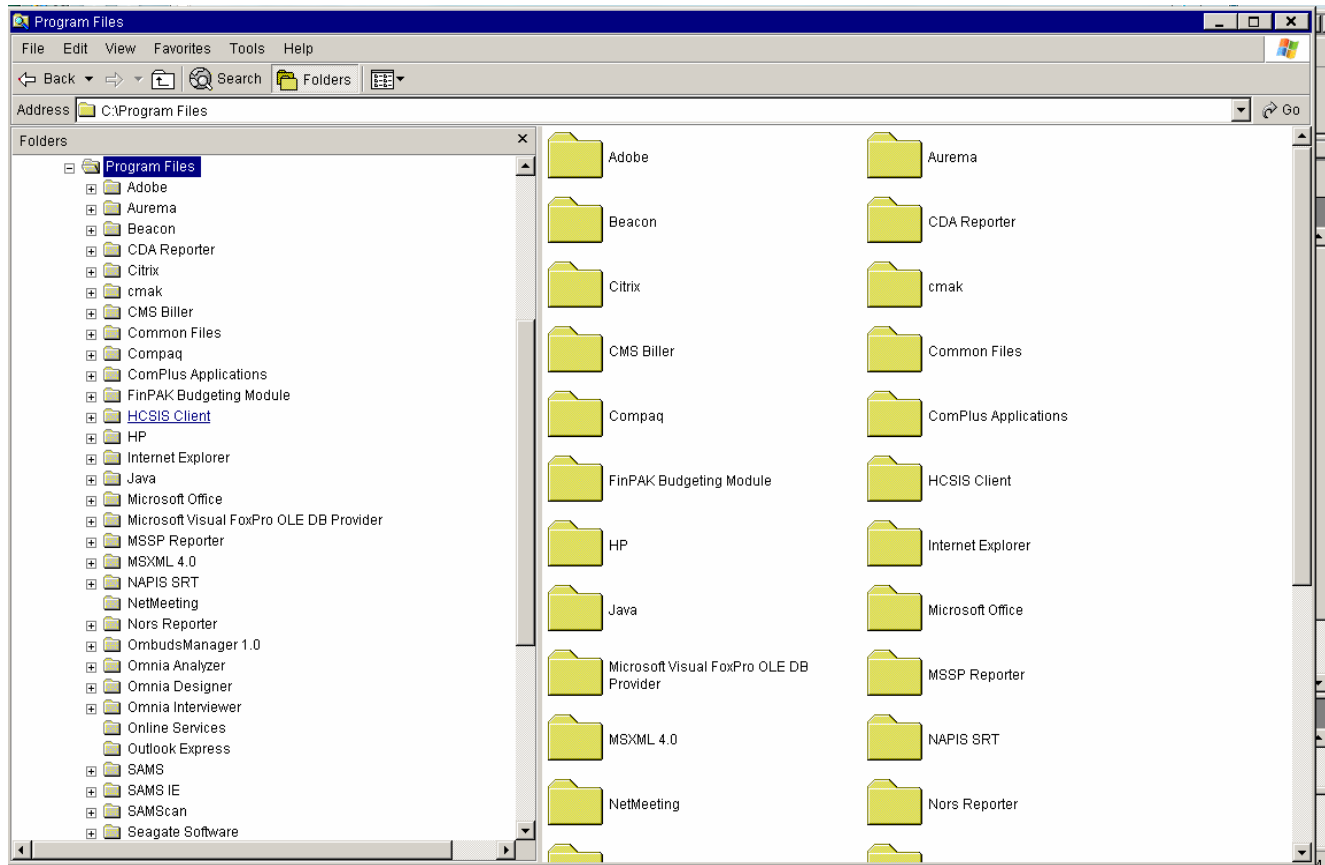
Nationally, implementation (and even study) of the patient identifiers has been legislatively blocked for the last ten years and largely forgotten. The demise of the DHFS Center for Uniformity, Security and Privacy (CUSP) due to budgetary constraints, has left a gap in institutional memory of the data stewardship program that once was. In my open records request, I went on to say that the eHealth Care Quality and Patient Safety Board should consider recommending a law that would prohibit state or local agencies from circumventing ADM12, HIPAA and state privacy and open meetings laws through their placing the electronic records in data centers outside the State of Wisconsin and that the principles of responsible data stewardship should be reviewed by all DHFS staff.

Wisconsin has been a leader among states in the development of health and social service programs and as a result of work by its eHealth Care Quality and Patient Safety Board, established by Governor Doyle in 2005, is poised to the leader in implementing health information technology (HIT) and developing health information exchanges (HIE) and electronic health records (EHR). One recent newspaper article included an observation by a health care activist that Dane County could become the Silicon Valley of electronic health records in the next few years. Health care information providers including Epic, GE Health Care, Metavante and Symphony are members of the board. Yahoo, Google, Microsoft and many smaller leading edge software and information entities are located in Dane County. The Morgridge Institute for Research funded by John Morgridge, chair of the board of Cisco, will open in 2010.

Because of Wisconsin's leadership role and the likelihood of it being a star in the progressive movement in health care programs, the Social Assistance Management System (SAMS) utilized by Wisconsin's Area Agencies on Aging possibly will be assumed as meeting consumer empowerment standards such as those being specified by the American Health Information Community (AHIC) relating to consumers' personal health records (PHR). Because of the standards of excellence that are routinely met throughout

Wisconsin by its private and governmental agencies, just being identified as from Wisconsin carries with it a reputation for quality and an assumption of meeting/surpassing standards.

An examination of SAMS and Agingnetwork.com, however, clearly reveals that rather than being constructed following standards, a number of independently developed applications are accessed with the SAMS application acting as a patient-centric hub. All data integration efforts involving applications that were independently developed encounter unexpected problems. The screen shot below of program files on Harmony's host computer shows a number such applications that can be linked to person specific records in SAMS which (I believe) were originally developed independently of one another.



The copy of the SAMS contract with Wisconsin's Bureau of Aging and Disability Resources (BADR) indicated that the cost of the annual license for the software was \$20,000. The NAPIS SRT (National Aging Program Information System - State Reporting Tool) is provided by the Administration on Aging (AoA) free of charge to state and local aging agencies. Documentation of SAMS and related applications including copies of all sessions of the Harmony/Synergy 2007 Conference was made available on a Web site called [www.dhfsbadr.org](http://www.dhfsbadr.org) that I initially believed to belong to the Department of Health and Family Services but which I later found to be privately owned by the Wisconsin's SAMS data administrator. At this point, all information has been removed.

Participation in the Harmony/Synergy's conferences by AoA staff has created a sense that Harmony's suite of applications are AoA's National Aging Program Information System (NAPIS). The Administration on Aging's (AoA) excellent reputation carries with it, as does Wisconsin's, an assumption of meeting or surpassing all standards. But AoA has not defined a minimum data set (MDS) that would meet both local and federal needs. The problems related to relying upon the state and local aging programs (without federal guidance) to be responsible for information systems are well documented in the

study prepared for the National Association for State Units on Aging in December 2006, entitled, *State Information Systems Management Study*. That study can be found on the AoA Web site at: <http://www.aoa.gov/about/results/Information%20Systems%20Management%20Study.pdf> The SAMS system is cited in that study as being used by the majority of states but, depending upon their organizational relationships with HIPAA covered entities, different approaches are followed regarding data sharing activities.

Following is the table of contents of the 2007 Synergy User's Conference, which was held in August 2007, the same month that I began my volunteer data entry position. I utilized these files, which the SAMS administrator had placed on his Web site (and which I copied to CD) and the SAMS Manual along with hands on training by my predecessor, to learn about SAMS. The documentation of the user's conference by the SAMS administrator is the most detailed documentation of any conference that I've ever reviewed. The documentation is so complete, and because I can access and study any portion of it at any time, I likely have a better grasp of SAMS than do most of the on-site participants in the conference.

### **Synergy User's Conference, August 2007**

**NOTE:**

Although you can click on certain file types and open them directly within your web browser, this is not recommended because you will experience slow performance. For PDF, Word (.doc), and Excel (.xls) files, follow these steps to save a document to your local hard drive and view it from there.

- (1) RIGHT-click on the hyperlink below.
- (2) Depending on your web browser, select [Save Target As] or [Save Link As].
- (3) Save the file to your local hard drive - usually your C:\ drive.
- (4) Use Windows Explorer to navigate to the saved file on your hard drive and open it from there.

Section	Session Description	Size	Document Description
Introduction	Opening Session	1851 KB	<a href="#">Stan Eames - Opening Statement</a>
		2980 KB	<a href="#">Tom Laba - Opening Statement</a>
		1093 KB	<a href="#">Valerie Cook, AoA - Measure for Measure</a>
State and Federal Panel Discussion	Bob Hornyak, AoA - Modernization of the Older Americans Act	411 KB	<a href="#">Presentation</a>
		4578 KB	<a href="#">Handout - AoA Strategic Action Plan 2007-2012</a>
		21383 KB	<a href="#">Audio Clip (91 minutes)</a>
SAMS Track Sessions	Success with NAPIS (Chris Burdick)	227 KB	<a href="#">Agenda</a>
		3893 KB	<a href="#">Presentation</a>
		609 KB	<a href="#">Handout 1 - NAPIS Reporting Requirements</a>
		818 KB	<a href="#">Handout 2 - SAMS Family Caregiver Addendum</a>
		262 KB	<a href="#">Handout 3 - Recording NAPIS Data</a>

		<a href="#">Elements in SAMS</a>
Moving beyond NAPIS (Alan Perry)	225 KB	<a href="#">Part 1 - Agenda</a>
	2532 KB	<a href="#">Part 1 - Presentation</a>
	1841 KB	<a href="#">Part 1 - Handout</a>
	224 KB	<a href="#">Part 2 - Agenda</a>
	1112 KB	<a href="#">Part 2 - Presentation</a>
	6573 KB	<a href="#">Part 2 - Handout</a>
The Resource Center Model (Jim Sackett)	225 KB	<a href="#">Agenda</a>
	4973 KB	<a href="#">Presentation</a>
	5278 KB	<a href="#">Handout 1 - Comprehensive Solutions for the ADRC Model</a>
	572 KB	<a href="#">Handout 2 - Web-Based Data Management from Synergy</a>
	1612 KB	<a href="#">Handout 3 - BeaconWEB</a>
	1099 KB	<a href="#">Handout 4 - SAMSapp</a>
	1105 KB	<a href="#">Handout 5 - SAMScdi</a>
Comprehensive Model for Home and Community Based Care (Jim Sackett)	227 KB	<a href="#">Agenda</a>
	4061 KB	<a href="#">Presentation 1</a>
	2351 KB	<a href="#">Presentation 2</a>
	692 KB	<a href="#">Handout 1 - SAMS Plus BenefitsCheckUp</a>
	3271 KB	<a href="#">Handout 2 - CMS Biller</a>
	40 KB	<a href="#">Handout 3 - SAMS Reports</a>
	2727 KB	<a href="#">Handout 4 - Technologies for the Integration of Human Services Data</a>
	756 KB	<a href="#">Handout 5 - Community-Based Care Tools</a>
	5429 KB	<a href="#">Handout 6 - Comprehensive Solutions for the Point of Entry Model</a>
Deployment Management Strategies (Alan Perry)	225 KB	<a href="#">Agenda</a>
	1655 KB	<a href="#">Presentation</a>
	134 KB	<a href="#">Handout</a>
Using SAMS for Medicaid Services (Chris Burdick)	452 KB	<a href="#">Handout 1 - SAMS Fund IDs and Unit Distribution</a>
	756 KB	<a href="#">Handout 2 - Community-Based Care Tools</a>
SAMS Comprehensive Reports	226 KB	<a href="#">Agenda</a>

	(Jim Sackett)	1241 KB	<a href="#">Presentation</a>
		40 KB	<a href="#">Handout</a>
	SAMS Admin for Experts (Chris Burdick)	228 KB	<a href="#">Agenda</a>
		3573 KB	<a href="#">Presentation</a>
		254 KB	<a href="#">Handout 1 - Using SAMS Security</a>
		5105 KB	<a href="#">Handout 2 - SAMS Security Examples</a>
		9920 KB	<a href="#">Audio Clip 1 (42 minutes)</a>
		11495 KB	<a href="#">Audio Clip 2 (49 minutes)</a>
	SAMS Admin for the Rest of Us (Alan Perry)	223 KB	<a href="#">Part 1 - Agenda</a>
		854 KB	<a href="#">Part 1 - Presentation</a>
		223 KB	<a href="#">Part 2 - Agenda</a>
		1546 KB	<a href="#">Part 2 - Presentation</a>
		1528 KB	<a href="#">Handout</a>
	The Next Generations of the System (John Byer)	836 KB	<a href="#">Presentation</a>
	SAMS 1.9 Overview (Tom Laba)	225 KB	<a href="#">Agenda</a>
		280 KB	<a href="#">Presentation</a>
752 KB		<a href="#">Handout - SAMS 1.9 Release Preview</a>	
15536 KB		<a href="#">Audio Clip (66 minutes)</a>	
Side Sessions	Care Planning and Service Orders (Max Wilcox)	227 KB	<a href="#">Agenda</a>
		833 KB	<a href="#">Presentation</a>
		1331 KB	<a href="#">Handout</a>
	Designing Assessment Forms and Indicators (Max Wilcox)	227 KB	<a href="#">Agenda</a>
		1249 KB	<a href="#">Presentation</a>
		183 KB	<a href="#">Handout 1 - Omnia Indicator Functions and Operators</a>
		30 KB	<a href="#">Handout 2 - SAMS-Omnia Linked Items 2007</a>
		1689 KB	<a href="#">Handout 3 - Omnia Designer</a>
		593 KB	<a href="#">Handout 4 - Omnia System</a>
		153 KB	<a href="#">Handout 5 - Omnia Catalog 1.2.5 Update Notes</a>
	FinPak Demo (Alan Perry)	224 KB	<a href="#">Agenda</a>
		1178 KB	<a href="#">Presentation</a>
		41 KB	<a href="#">Handout</a>

	Omnia Assessment Technology (Max Wilcox)	229 KB	<a href="#">Agenda</a>
		695 KB	<a href="#">Presentation</a>
		475 KB	<a href="#">Handout 1 - Omnia Interviewer Import-Export Guide</a>
		30 KB	<a href="#">Handout 2 - SAMS-Omnia Linked Items 2007</a>
		526 KB	<a href="#">Handout 3 - Omnia CE</a>
		610 KB	<a href="#">Handout 4 - Omnia Interviewer</a>
		593 KB	<a href="#">Handout 5 - Omnia System</a>
	SAMS Unit Distribution (Max Wilcox)	225 KB	<a href="#">Agenda</a>
		968 KB	<a href="#">Presentation</a>
		269 KB	<a href="#">Handout 1 - Fund IDs and Unit Distribution</a>
		727 KB	<a href="#">Handout 2 - Unit Distribution</a>
	The New Beacon (Max Wilcox)	227 KB	<a href="#">Agenda</a>
		34 KB	<a href="#">Handout - BeaconWEB Export Requirements and Data Fields</a>
		10852 KB	<a href="#">Audio Clip (46 minutes)</a>
	Using Rosters (Alan Perry)	225 KB	<a href="#">Agenda</a>
		421 KB	<a href="#">Presentation</a>
		1367 KB	<a href="#">Handout</a>
	SAMS Import and Export (Max Wilcox)	226 KB	<a href="#">Agenda</a>
		1799 KB	<a href="#">Presentation</a>
		31 KB	<a href="#">Handout 1 - SAMS Import-Export Release Notes, v 2.5.4</a>
		25 KB	<a href="#">Handout 1 - SAMS Import-Export Release Notes, v 2.6.2</a>
		440 KB	<a href="#">Handout 3 - SAMS XML Specification for NAPIS Data</a>
		959 KB	<a href="#">Handout 4 - SAMS Import-Export Utility, User's Guide</a>
		17 KB	<a href="#">XML Demo 1 - Consumer Caregiver using Descriptor</a>
		20 KB	<a href="#">XML Demo 2 - Consumer Caregiver using Reference</a>
		28 KB	<a href="#">XML Demo 3 - Consumer Data</a>
		15 KB	<a href="#">XML Demo 4 - Delivery by Caregiver</a>
		15 KB	<a href="#">XML Demo 5 - Delivery Data using</a>

			<a href="#">Descriptor (No Consumers)</a>
		20 KB	<a href="#">XML Demo 6 - Delivery Data using Reference (With Consumers)</a>
		18 KB	<a href="#">XML Demo 7 - Delivery Data with Daily Details</a>
		17 KB	<a href="#">XML Demo 8 - Delivery for Caregiver (Reciprocal)</a>
		28 KB	<a href="#">XML Demo 9 - Hawaii County Example</a>
		9135 KB	<a href="#">Audio Clip (39 minutes)</a>
Enhancement Committee Meetings	Beacon (Tim Riley)	52 KB	<a href="#">Handout 1 - Enhancement Requests, BeaconIR</a>
		11 KB	<a href="#">Handout 2 - Enhancement Requests, BeaconWEB</a>
	SAMS (Tom Laba)	223 KB	<a href="#">Agenda</a>
		280 KB	<a href="#">Presentation</a>
		115 KB	<a href="#">Handout 1 - Enhancement Requests, SAMS</a>
31 KB	<a href="#">Handout 2 - Enhancement Requests, Interviewer (assessments)</a>		
Customer-Led "Best Practices" Sessions	Bryan Cobb and Anne Varnum, Northern Kentucky Area Development District	3732 KB	<a href="#">Presentation</a>
Partner Sessions	MJM Innovations - SAMS Senior Center and SAMScan Swipe	225 KB	<a href="#">Agenda</a>
		6676 KB	<a href="#">Presentation</a>
		174 KB	<a href="#">Handout 1 - SAMScan</a>
		33 KB	<a href="#">Handout 2 - SAMS Senior Center</a>
		32 KB	<a href="#">Handout 3 - SAMScan Swipe</a>

As there is confusion as to whether the SAMS application is the AoA information system, there is confusion at the state level as to whether SAMS is the official State of Wisconsin information system for Family Care which combines at least eight different funding sources into a comprehensive program for long term care. Older American Act funding is likely the smallest funding source but because the nutrition programs are the gateway programs to more care intensive programs, the SAMS information system serves as the gateway to patient-centric information in other systems.

Following is an excerpt from email BADR sent to all SAMS users on October 24, 2008 which would allow Social Security Numbers and SAMS IDS to be copied to Excel workbooks. Even though the procedure is prompted by the best of intentions, it is completely contrary to good data stewardship principles and should not be permitted.

*“As you may notice in the video documentation, I&A functionality now exists in SAMS; it is referred to as the "SAMS IR" section of SAMS. However, Wisconsin is not yet using this piece of SAMS - meaning that you cannot yet see it or test it in SAMS. Wisconsin organizations*

*currently using Beacon will continue to do so for some time yet. A migration of all Beacon data into SAMS is in the works; however, this will likely not occur for at least another couple of months. We (Wisconsin) are presently waiting for Harmony to implement additional, necessary I&A-related functionality into the SAMS IR screens. Once that has been done, we'll perform quite a bit of initial testing. Then we'll migrate real-world Beacon data into SAMS for a single pilot ADRC. After the pilot ADRC has had time to test and confirm that their data migrated successfully, the migration rollout can be defined and scheduled.*

*As has been mentioned in previous emails, we plan to run a script which will "scrub" social security numbers from the SAMS database. (This does NOT include the SAMS benefit specialist database.) In order to ensure optimal accuracy during the upcoming Beacon-to-SAMS migrations, this SSN scrub will be performed AFTER the Beacon-to-SAMS migrations have all been completed. (This is likely several months from now.) Some current users have expressed a desire to have continued access to SSN's which are currently stored in SAMS and/or Beacon. (The stated reason is the need to be able to look up client information in other data systems via SSN.) If you believe that you absolutely MUST retain SSN data which currently exists in SAMS and/or Beacon, please wait until after your Beacon migration has been completed. Then - at your discretion - you can perform an extraction of data from SAMS which would, e.g., list ONLY the SAMS user ID's and SSN's next to each other in some other medium (e.g., an Excel workbook). I am not endorsing this method of data retention; rather, I am merely pointing out that the option is available if your particular organization decides that it is absolutely necessary (and appropriate). If you want more information on the easiest way to extract this data, please call me."*

I have been involved with the management information systems related to health and social services since the 1960's. I retired in 1994, from a career position as chief of research and statistics for a division then located in the Wisconsin Department of Health and Family Services (DHFS). Just preceding retirement, I earned a technical degree in programming and systems analysis degree and established my own consulting and software development company. I primarily use the resources of my company to inform my work efforts in post-retirement and volunteer positions in the public sector.

Post "retirement" positions (among others) included serving as systems development supervisor for the office of systems and data processing for the Wisconsin State Supreme Court, linked database programmer and analyst for the Center for Health Statistics (CHS) located in a division in DHFS and (from 1998 until 2005) a position as in-house data administrator/consultant for the Center for Uniformity, Security, and Privacy (CUSP), also located in a division in DHFS. In March 2008, I reconstituted my company, originally established in 1993, as a limited liability corporation named "Metasteward LLC".

The name of my company is a shortened version of "metadata steward" and is derived from expertise in applying the principles of ISO/IEC 11179 which is formally known as the ISO/IEC Metadata Registry (MDR) standard. While employed by DHFS/CUSP, I participated on behalf of DHFS in the HIPAA Metadata Registry Consortium and in support of establishing the DHFS Data Stewardship Council was the registrar for (beta version) MetaPro, a distributable metadata registry (that was programmed in MS Access 97). I actively participated in and was the agency liaison to HL7 in its capacity as a standards setting organization (SDO) for HIPAA. The data registry consortium was composed of individuals from a number of federal organizations, Minnesota and Wisconsin state agencies, and several private

enterprises along with Oracle Consulting (who had programmed the metadata registry). The beta version of MetaPro was sponsored by the (then) Health Care Financing Administration (HCFA) and the Environmental Protection Agency (EPA).

Now, the opportunities for participation in standards activities at the national level over the Internet allow me to draw upon my “legacy” experiences to guide my company. Metasteward LLC’s mission is to become the “organization of choice” for consultation on defining and recommending consumer empowerment and protection standards and to be recognized as one of the leading privacy advocates for seniors and the disabled. As a member of the American National Standards Institute (ANSI), I participate in Web based conferences and symposia (and study event transcripts) such as the Medical Identity Theft Town Hall that was held in October 2008. I am a participant (via Web and telephone) in the Health Information Technology Standards Panel (HITSP) activities such as reviewing “*Consumer Preferences – Draft AHIC Extension/Gap*” that is open for public feedback until March 11, 2009. I participated in the February 17, 2009, event - *From E-Gov to Connected Governance: the Role of Cloud Computing, Web 2.0 and Web 3.0 Semantic Technologies* and reviewed *Privacy in the Clouds: Risks to Privacy and Confidentiality from Cloud Computing* published on February 23, 2009 by the World Privacy Forum. I participate in the monthly HITSP webinars and (again via the Web) attend meetings of Wisconsin’s eHealth Care Quality and Patient Safety Board and have reviewed past reports from its sub-committees.

However, in spite of my background and expertise in data administration, my comments and observations are dismissed by saying that I misrepresent the conscientious administration of the program. The emails (shown below) are those that I received in response to my complaint sent to Wisconsin’s director of information security:

*From: "Lettman, Mike J - DOA" <mike.lettman@wisconsin.gov>  
To: "fredbuhr@merr.com" <fredbuhr@merr.com>  
Date: Thu, 8 May 2008 16:52:47 -0500  
Subject: RE: Serious Security Problem*

*Hello Mr. Buhr*

*Thank you for your inquiry concerning security and privacy on DHFSBADR.org. The Dept of Health and Family Services (DHFS) and their vendor(s) are fully responsible for that particular site, application and the information it contains. We have forwarded your request to the DHFS and asked them to respond with answers to your questions.*

*Attached is a response from the DHFS. If you have any further security or privacy questions or concerns about this site you should raise those directly with the DHFS. DHFS has provided the following contact for you:*

*Kathy Johnson  
DHFS Privacy Officer  
608-266-5484  
johnskl@dhfs.state.wi.us*

*Thanks again for contacting us concerning this matter.*

*Mike Lettman*

*Director of Information Security  
Office of Security  
Division of Enterprise Technology  
Wisconsin, Department of Administration  
P.O Box 7836  
Madison, WI 53707-7836  
Voice:(608) 224-3898*

*Response to Mike J. Lettman, DOA  
DATE: May 2, 2008  
RE: email from Fred Buhr April 30, 2008  
SUBJECT: Alleged "Serious Security Problem"*

*Fred Buhr, a volunteer at the McFarland Senior Center, presents a series of assertions in this email which significantly misrepresent the conscientious administration of the Older Americans Act programs in the Bureau of Aging and Disability Resources (BADR) in DHFS. Staff in BADR has been respectful and attentive to Mr. Buhr's concerns for several months.*

*BADR has contracted with Area Agencies on Aging to secure the services of Karl Schlenker to administer the SAMS Older Americans program information system. Karl is supervised by an experienced manager in BADR. Policy memoranda, user guides, technical assistance and information about updates from the software provider (Harmony) are issued by BADR via email to all SAMS users. Karl is the primary author or distributor of the information*

*As a convenience to SAMS users, Karl set up an Internet site where he deposited the memos and material in response to frequently asked questions. The site includes training videos related to use of SAMS. All material is previously published and available from other sources. No secure or private personal information is presented on the site. The site was established without following protocol for DHFS web postings. The Bureau has begun transferring the SAMS information to the DHFS website, at which time the stand-alone website will be shut down. Harmony has not participated in the development or maintenance of the website. Further, Karl has not benefited in any way from managing this website, which is merely a repository of work materials for users.*

- *Mr. Buhr asserts that Karl is Harmony's sole administrator for SAMS in Wisconsin. This is not true. Karl is not a Harmony employee. Karl is Wisconsin's primary (but not sole) administrator for SAMS.*
- *Mr. Buhr asserts that Harmony provided Karl with a development environment to test Harmony's products. In fact, Karl declined the offer to participate.*
- *Mr. Buhr asserts that policy for the nutrition program has only been posted on Karl's internet site. This is not true. A manual of policies and procedures has been published by BADR.*
- *Mr. Buhr asserts that the Secretary has not approved content for the BADR Internet site as is required. The Secretary does not approve all web postings; this responsibility is delegated to the*

*divisions. All material posted as policy was approved by management within the Division of Long Term Care/Bureau of Aging and Disability Resources.*

- *Mr. Buhr asserts that Harmony and BADR are one and the same. This is not true. The Bureau of Aging and Disability Resources is an agency within the Department of Health and Family Services, designated as the single state agency on aging by the federal Administration on Aging. The Bureau has a contractual relationship with Harmony.*
- *Mr. Buhr asserts the every report listing participants by data entry operators is a breach of privacy for all persons listed in the report. This is not true. SAMS users can only see the names of individuals who are participants in their programs. County aging offices and their service providers are covered by the same confidentiality provisions that apply to all public human services programs.*
- *Mr. Buhr asserts that hundreds of thousands of individuals have had their privacy breached an astronomical number of times. This is not true. Repeated claims to that effect can only serve to falsely alarm senior citizens and should be vigorously denied.*
- *Mr. Buhr asserts that Harmony and BADR (DHFS) have not followed state laws or security standards and the SAMS system is vulnerable. We are aware of no violations of state law. Further, we expect that the forthcoming Third Party Security audit at Harmony will document the integrity of the system.*
- *Mr. Buhr asserts that his rights to serve as a data entry operator were revoked for a “poorly fabricated reason.” This is not true. Mr. Buhr informed Secretary Timberlake and Secretary Morgan in a correspondence received April 23, 2008, that he would suspend his data entry tasks as a volunteer because of his concerns about the SAMS system. Because he stated his intention to discontinue entering data, there is no need for him to maintain a password. Good security practice would suggest that when a staff member (or volunteer) resigns from his duties, his password should be revoked. Therefore, the password used by Mr. Buhr was changed as a standard security measure. This action was taken in consultation with McFarland Senior Center and Dane County.*
- *Mr. Buhr asserts that he and hundreds of thousands of Wisconsin’s citizens, and hundreds of millions nationwide have had their privacy breached countless times. We are not aware of any documented security breaches of SAMS.*

I resumed my volunteer data entry duties after a hiatus of three months due to the difficulty in securing a replacement. Contrary to Ms. Johnson’s assertion, since McFarland only has one login, it was the password of McFarland’s outreach director that was changed and was done without consulting her.

In my email to the Wisconsin’s director of information security, I raised the question as to which entity would financially be held responsible for the potential damages related to systemic security breaches. Although it is clear to me that “cyber thieves” have the technology to download and maliciously exploit information from all the files that I saw represented by icons, state administrators cling to the belief that there is no danger until there are “documented security breaches of SAMS”. My question remains: “In the unthinkable event that the personal health information of millions of seniors and disabled gets into the hands of “cyber thieves”, who is financially responsible for the damages which could total in the hundreds of billions of dollars?”

My original contact with state and local SAMS administrators related to my concerns about violation of individuals’ rights to privacy through misusing the DETERMINE Nutritional Health Form as an assessment tool to measure nutrition program effectiveness. In March 2008, I met with local and state

staff and utilized an AoA PowerPoint presentation entitled *Measure for Measure* (from the opening session of the 2007 user's conference) which clearly defined the assortment of measures that AoA intended to use to evaluate increased program efficiencies and improved client outcomes. Not one measure related to any of the ten questions, answers to which are recorded and compared year to year. The form (on page 2) asks the following questions identified by the name of the data entry fields as depicted below.

		YES
QI 01	<b>I have an illness or condition that made me change the kind and/or amount of food I eat.</b>	<b>2</b>
QI 02	<b>I eat fewer than 2 meals per day.</b>	<b>3</b>
QI 03	<b>I eat few fruits or vegetables, or milk products.</b>	<b>2</b>
QI 04	<b>I have 3 or more drinks of beer, liquor or wine almost every day.</b>	<b>2</b>
QI 05	<b>I have tooth or mouth problems that make it hard for me to eat.</b>	<b>2</b>
QI 06	<b>I don't always have enough money to buy the food I need.</b>	<b>4</b>
QI 07	<b>I eat alone most of the time.</b>	<b>1</b>
QI 08	<b>I take 3 or more different prescribed or over-the-counter drugs a day.</b>	<b>1</b>
QI 09	<b>Without wanting to, I have lost or gained 10 pounds in the last 6 months.</b>	<b>2</b>
QI 010	<b>I am not always physically able to shop, cook, and/or feed myself.</b>	<b>2</b>
	<b>TOTAL</b>	

I pointed out that the form, as found in the 2002-2004 Geriatrics Review Syllabus (GRS) included the instructions to “Circle the number in the “YES” column for those that apply to you or someone under your care.” This was a clear indication that the form was intended to be interpreted by a health care professional rather than being entered into an individual’s electronic health record. Furthermore, discussion with the nutrition specialist revealed, that we both knew and agreed, that the form had never been validated for use with the elderly. Also, I noted that the form in the GRS had been reprinted with permission of the Nutrition Screening Initiative while the form being used by Dane County did not carry any indication that it was being used with permission.

The statement below found at the bottom of the form does not appear to me to be true as none of the nutrition questions are eligibility factors for the nutrition programs.

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 refused to provide this information. If you have questions regarding this, please call the Area Agency on Aging of Dane County at 261-9700.

My main emphasis as a privacy advocate is that everyone should be given the opportunity to be the steward of their own personal health information. Everyone should be permitted to give or deny informed consent for specific uses of their health data. There is a vast discrepancy between the administrative methods of collection of individuals’ health assessment information between programs funded under titles of the Social Security Act subject to HIPAA (such as Medicare) and those funded under titles of the Older Americans Act (such as the congregate meal program). State Units on Aging (SUA) and local Area Agencies on Aging (AAA) are (in my opinion) egregiously violating consumers privacy rights to informed consent by collecting and storing personal health assessment information in electronic databases with a misleading statement on forms saying, “The information you are being asked to provide is need to determine if you are eligible to receive Older Americans Act Service and to comply with federal reporting requirements.”

President Obama’s stimulus legislation includes *Title XIII – Health Information Technology of the “American Recovery and Reinvestment Act of 2009”* which provides for improved privacy and security provisions for health information not covered under previous laws. While management information systems holding person specific health care records collected for AoA programs might not have been subject to standards in the past, I believe they will be in the future. But even if that is the case, under a “normal” time frame it will be years before all the variations in information systems are reconciled and the personal health information (PHI) of nutrition program participants becomes part of the national health information infrastructure. However, the time frame could be dramatically shortened if the Administration on Aging (AoA) would simply acquire all the commercial software, hardware and data assets (including backup systems) of the vendors now contracting with state and local aging programs and establish a single reporting system.

*Appendix C of the NASUA State Agency Information Systems Management Study* includes the following commercial software summaries and overviews:

- SAMS 2000 \*
- Advanced Information Manager (AIM)
- NAPISCare (RTZ Associates)
- QContinuum Product Overview
- Innovative Systems
- PeerPlace

\*Harmony Inc. acquired Synergy Software Technologies after the date of this study and is currently the owner of the software, hardware and data assets related to the SAMS2000 product line.

In the stimulus package under “*Subtitle B—Incentives for the Use of Health Information Technology*” there is provision for immediate funding to strengthen the health information infrastructure. I believe that total amount for investment in the health care information infrastructure is \$20 billion dollars. A modest grant from that appropriation to AoA enabling it to purchase all the current commercial software and develop a single integrated information system would have likely have a huge return on investment (ROI). If only a fraction of the hundreds of millions of dollars of medical fraud and medical identity theft were prevented by through implementation of a single secure management information system, the system would more that pay for itself. I believe an objective rudimentary security and privacy risk assessment of the current mix of systems would show enough savings to justify a modest investment.

Earlier in this email, I mentioned my conversations with local and state nutrition program staff and that we agreed that the DETERMINE Nutrition Screening Form had never been validated for use with elderly clients. Since then, I have researched the issue further and found a study reported in the August 1997, issue of the Journal of the American Dietetic Association that indicated the tool should not be used by dietitians and care-givers as a screening tool for nutritional risk in the elderly. The study written by four researchers from the Human Nutrition Research Center on Aging at Tufts University said that the data suggested that using the Nutrition Screening Initiative (NSI) checklist as a screening tool may ignore some risk factors that could be eliminated or delayed by intervention. 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.

The Tufts researchers compared the DETERMINE questionnaire with a nutritional status survey on nearly 600 Boston residents age 60 and older from 1981 to 1984. The researchers found that only 45.8 percent of the respondents who reported poor health in the original survey would have been identified with the DETERMINE questionnaire. More significantly, the DETERMINE checklist would have uncovered only 36.2 percent of persons who reported low nutrient consumption in the previous survey.

I mention the Tufts' study at this point because the data assets collected through the commercial software products and held in storage, either locally or in a commercial data warehouse, if purchased by AoA would provide a wealth of health information, consisting of millions of longitudinal assessments that researchers only dream of accessing.

from assessment data. When the following questions are answered the Nutrition Score is created automatically. Those consumers with a score of 5 or higher are assigned a High Nutrition Risk status.

Question Name	Catalog ID	Weight of 'Yes' response
Changes in eating habits	2383	2
Eats <2 meals	1108	3
Eats < 5 servings of fruits or vegetables daily	2384	1
Eats < 2 servings of dairy	2385	1
Does not have enough money to buy food	1112	4
Chewing/swallowing problems	1818	2
Eats alone	1113	1
Takes 3+ drugs	1114	1
Lost or gained 10 pounds	1115	2
Not always physically able	1116	2
Has 3+ drinks	1110	2

9. ADLs - The ADL count can be entered in the consumer record as pictured below. There is also an indicator that automatically calculates the ADL count from assessment data. When the following questions are answered the ADL count is created automatically.

Question Name	Catalog ID
ADL - Bathing performance (past 7 days)	1081
ADL - Dressing performance	1077
ADL - Eating performance (past 7 days)	1078
ADL - Toilet Use performance (past 7 days)	1079
ADL - Transfer performance (past 7 days)	1074
ADL - Walking in home performance	1076

10. IADLs - The IADL count can be entered in the consumer record as pictured below. There is also an indicator that automatically calculates the IADL count from assessment data. When the following questions are answered the IADL count is created automatically.

Question Name	Catalog ID
IADL - Meal preparation performance	1082
IADL - Shopping performance	1086
IADL - Managing medications performance	1084
IADL - Money management	1901
IADL - Rank Telephone Ability	3820
IADL - Heavy housework	1902
IADL - Light housekeeping	1903
IADL - Transportation performance	1087

**SAMS Consumer Record:** To see the location of these data elements – go to the list of consumers and double click to open a consumer record. You can then see the data elements within the consumer record there. Selecting Details in the contents menu will allow bring you to the 'General' section of the consumer record where you can see the NAPIS data elements.

If the SAMS system data were acquired and anonymized by AoA, the resulting data sets could provide years of research opportunities. Earlier, I mentioned the extensive planning efforts DHFS for implementation of HIPAA. Based upon algorithms that I developed when I was the “linked database analyst” in the DHFS Center for Health Statistics, I submitted a proposal for creating anonymous data public use data sets. Although it is ten years old, I believe the design is still relevant and could be used by any agency for data integration.

Service Delivery and Case Management Wednesday Morning Group

Agenda

August 12, 1998

1. Fred's brief on Data Integration in lieu of the DUOP--continued
2. Business plan subgoal 7.3--measurements
3. HIPAA update

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Future Items:

- Policy provision for informing clients on use of information (ala Dana)
- IRPW Statewide Database (w/Kris Freundlich)
- Track federal privacy legislation
- DUOP
- MEDS presentation (Wayne)
- OHCI Inet Query System demo (Barb)
- MDS presentation (via Mary or Richard Betz)
- Strategies for non-redundant information gathering and shared use (e.g. chargebacks)

## Data Integration

**Proposal:** The Department of Health and Family Services will follow a strategic data integration plan modeled upon the California approach incrementally building on existing projects and systems and systems that are about to be built.

In the fall of 1991, California identified critical problems in their health information systems. Although the following list is California's, some would say it only differs in degree from describing Wisconsin's situation this summer of 1998:

1. Access to available data is often inadequate, untimely, inconsistent, ineffective, and costly.
2. There is a lack of integral and adequate "bridges" between data sets, and among data providers, managers and customers.
3. Inadequate standardization exists due to lack of a single client I.D., common data set items and definition, standard procedures and coordinated data policies.
4. Present data gaps, overlaps, and uncertainties are costly for data providers, managers, and customers.
5. Data policies regarding confidentiality and security are inadequate or confusing.

California still has a ways to go to solve all the problems, but they adopted a strategy and plan for implementation that has proven to be sound. They followed an approach that allowed linkage of existing data sets and longitudinal tracking of clients. Adoption of the following proposals by the Department of Health and Family Services would capitalize on California's experience and put Wisconsin on a sound course.

**Proposal 1:** It is proposed that Secretary Leraan mandate that the following five core data elements and their standard (HIPPA compliant) data definitions be adopted by all Departmental and related local data sets:

Birth name of client  
Date of birth  
Place of birth (County if in Wisconsin, State if out of state, Country if out of USA)  
Mother's first name  
Gender

**Proposal 2:** It is proposed that the Department of Health and Family Services (DHFS) develop a standard client consent form to allow sharing of data for all DHFS programs using automated systems.

**Proposal 3:** It is proposed that the Department of Health and Family Services (DHFS) adopt (as appropriately modified) the Bureau of Health Care Finance's policies on confidentiality, memoranda of understanding between agencies, and training of staff regarding security and the sharing of information.

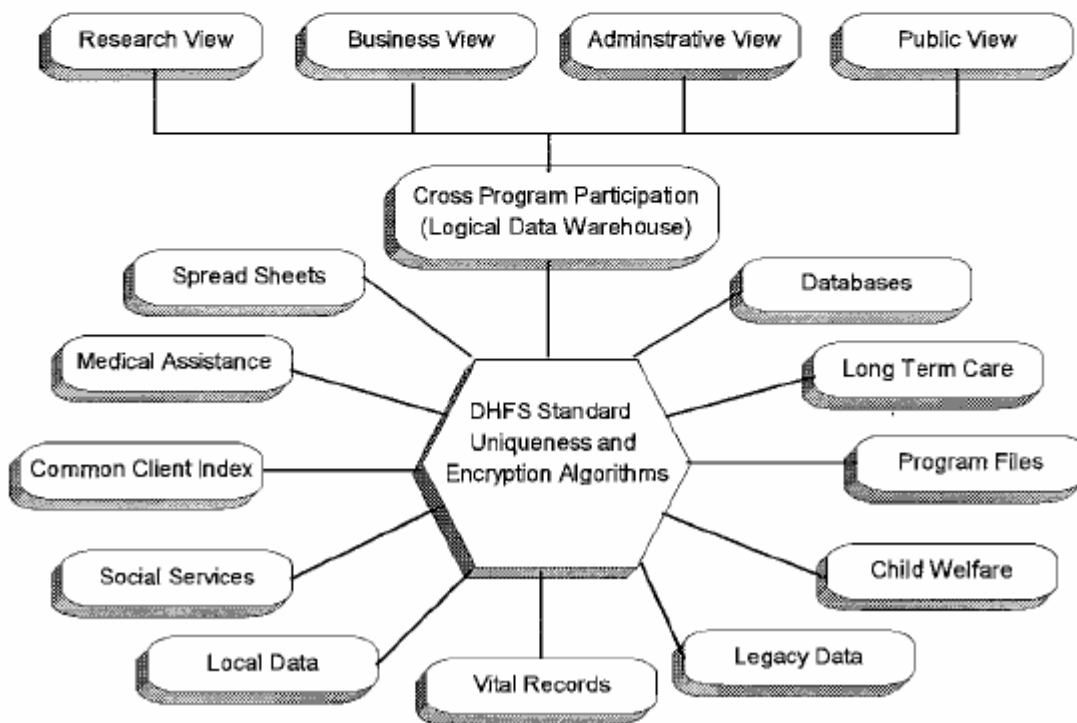
**Benefits to adopting these recommendations include:**

Immediate implementation in incremental steps.  
Modest implementation costs that can be absorbed without requesting additional budget authority.  
Reliable linkage across multiple data sets.  
Compatibility with all current and future client indices.  
Existing program data and record numbers can be maintained.

Proposal 4: It is proposed that Secretary Leean mandate the use of the following two standard algorithms by all Divisions within the Department and by all (related) local agencies:

- A. Standard person uniqueness algorithm (based upon the five core data elements)
- B. Standard name encryption algorithm (based upon the algorithm utilized by the Office of Health Care Information).

Adoption of this recommendation will permit unduplication of persons across programs and agencies while implementing a privacy (anonymous name) component. Views of logically integrated data, at various levels of aggregation and anonymity, are illustrated below:



I have documented my privacy and security concerns on my Web site located at: <http://www.metasteward.net>. Due to uncertainty whether my emails make it through all the filters, I would appreciate an acknowledgment if you receive this message.

Thank you.