INTEGRATING NEW MONITORING AND BEHAVIORAL SUMMARY METRICS INTO STANDARD PERSONAL HEALTH RECORD AND ELECTRONIC HEALTH RECORD SYSTEMS

By

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CERTIFICATE OF APPROVAL

This is to certify that the Master's Capstone Project of

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Has been approved

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Abstract

This paper investigates integrating new cognitive health coaching monitoring and behavioral summary metrics into standard personal health record and electronic health record systems. It is predicated on the reality of a rapidly increasing elderly population in the United States that is facing cognitive decline, and traditional healthcare infrastructure not being scaled to handle projected patient demand in the coming decades. The project is a derivative of an overarching program being conducted by Dr. Holly Jimison's team at Oregon Health & Science University. New variables are focused on three primary study categories: sleep management, cognitive health monitoring and remediation, and socialization. Specific aims are to define the new monitoring and behavioral summary metrics variables and their respective elements; research summary data representation in personal health record systems; and consult with various university professionals to understand which reports from the personal health record might be relevant and useful to clinicians using electronic health record systems. A mixed research methodology is composed of traditional information gathering techniques, personal interviews, and review of personal health record and electronic health record systems. Resultant findings indicate dashboard, graph, and chart formats should be employed and catered to the respective summary reporting preferences of health coaches and clinicians. Sample reports are available to the team for future implementation into a test or production infrastructure. Ultimately the desired outcome of this work is to assist patients to live relatively independent lives and maintain a sense of dignity during the aging process.

Introduction

A rapidly increasing elderly population in the United States is facing cognitive decline. Couple this fact with a traditional healthcare infrastructure that is not scaled to handle projected patient demand in the coming decades, and the result is a medical dilemma of unprecedented scope. Addressing the issue requires the concerted efforts and resources of the government, academic institutions, private enterprise, and non-profit research organizations.

Independent and collaborative cognitive health coaching studies have been conducted and many are currently underway. Their primary aim is to help prevent or delay age-related cognitive decline and dementias due to degenerative diseases. (Jimison & Pavel, 2007) These studies can also assist patients to live relatively independent lives and maintain a sense of dignity during the aging process. One such cognitive health coaching program is a joint effort between Oregon Health & Science University (OHSU) and the Oregon Center for Aging & Technology (ORCATECH). The study is in its second phase, wherein the focus is "developing a generalizable and scalable approach to integrating tailored cognitive health action plans for elders using a Web services architecture." (Jimison & Pavel, 2007)

This paper is based on the author's work with Dr. Holly Jimison's team at OHSU, and its partnership with ORCATECH. It will first define new monitoring and behavioral summary metrics variables for cognitive health coaching data. Then it will investigate integrating these variables as summary reports into Microsoft® HealthVault™ and Google™ Health personal health record (PHR) systems. Finally electronic health record

(EHR) system integration will be explored with the EpicCare® EMR, hereafter commonly referred to as Epic. New variables are focused on three primary categories: sleep management, cognitive health monitoring and remediation, and socialization.

Two main problems present themselves for dissection and resolution. The first problem is to develop a holistic approach to managing the health of older adults by focusing on disease management and home health. The newly proposed variables in this project introduce data types that have never been recorded in PHRs or EHRs. Our strategy consists of a two-pronged approach of defining the variables for different caregiver profiles and then summarizing this continuous data for storage in, and retrieval from, PHR and EHR systems. The second problem is to actually integrate the data into these systems. There is currently no model to support a standardized and scalable approach to integrating tailored health action plans, in general, for elders using a Web services architecture.

Background

Aging Cognitive Decline Demographics and Statistics in the United States

Overview

Alzheimer’s disease (AD), the most common cause of dementia, is used to illustrate the serious impact age-related illnesses have on the United States. AD is a degenerative, debilitating brain disorder with symptoms ranging from forgetfulness to pervasive neurological impairment that leads to death. Those living with AD lose their ability to function at home or at work, or to enjoy lifelong hobbies. Individual personalities change over time and body systems begin to malfunction. (Agronin, 2008)

2009 statistical facts and figures (Alzheimer's Association, 2009):

- There are 5.3 million people in the U.S. who live with Alzheimer’s disease.
- Someone develops the disease every 70 seconds.
- Alzheimer’s is the sixth-leading cause of death across all ages (5^{th} for those aged 65 and older).
- AD and dementia triple healthcare costs for Americans age 65 and older.
- Approximately $148 billion in direct and indirect medical costs each year are attributed to Alzheimer’s and other dementias.
- There are 9.9 million unpaid caregivers.

Gender

Alzheimer's disease affects both men and women. Estimates from the 2002 Aging, Demographics, and Memory Study indicate that 14% of all people aged 71 and older have dementia. (Plassman, Langa, & Fisher, 2007) Of people in this age group, the occurrence rate for women is 16% and 11% for men. The 2008 approximation shows that 2.4 million women and 1 million men aged 71 and older have dementia. However, "it appears that gender is not a risk factor for Alzheimer's disease or other dementia once age is taken into account." (Alzheimer's Association, 2009) Because there are more women than men who live to be 71 or older, there are a higher number of cases associated with women in this age bracket.

Education

Studies of the prevalence of AD show that differences in education level are relevant. People with fewer years of education appear to have higher rates of the disease. (Alzheimer's Association, 2009) This same group also has a greater risk of developing AD. People with less than 12 years of education are 15% more likely to develop dementia than people with 12 to 15 years of education. Even more significant, the risk of developing dementia becomes 35% for people with less than 12 years of education when compared to people with more than 15 years. These percentages correlate with the findings of AD alone. Lower education levels are normally attributed to related socioeconomic factors such as less access to medical care and higher unemployment rates.

Regions and States of Residence

There is substantial variability by state and region for people 65 years and older who have Alzheimer’s disease. California, Texas, Illinois, New York, Pennsylvania and Florida each had between 201,000 and 499,000 cases of AD in 2000. (Alzheimer's Association, 2009) They are some of the most populous states but the rates of occurrence are noteworthy. From 2000 to 2025, most states and regions should see double-digit percentage increases in AD. The South, Midwest and West could experience increases of 30-50% and greater in this same period. Alaska, Colorado, Idaho, Nevada, Utah and Wyoming are projected at a 50% increase or more for the incidence of AD in their populations aged 65 and older. Such projections will have a greater impact on healthcare systems and government infrastructure as these numbers rise.

Mortality

Generally speaking, “underreporting of Alzheimer’s disease as an underlying cause of death is well documented.” (Alzheimer's Association, 2009) Death rates vary across states due to differences in demographics and respective reporting practices. The CDC National Center for Health Statistics reported that in 2000 heart disease caused over 710,000 deaths in the United States. (Minino, Arias, Kochanek, Murphy, & Smith, 2002) Stroke ranked second with nearly 168,000 deaths and AD was third with just under 50,000. AD was one of the most radically changing figures, jumping by 47% to 73,000 deaths in 2006. The other two causes declined in that six-year period.

Alzheimer’s disease death rates per 100,000 people are notable. In the 75-84 age group, the overall rates were 139.6 in 2000 and 177.3 in 2005. (Alzheimer's Association, 2009) AD figures for those 85 and older were markedly higher with 667.7 in 2000 and 861.6 in 2005. The 2005 death rates (per 100,000) by race and gender were:

- Non-Hispanic Black: Male = 7.2; Female = 16.9
- Hispanic: Male = 3.5; Female = 7.0
- Non-Hispanic White: Male = 18.5; Female = 44.8

Kung, et al stated, “The lower death rates in non-Hispanic blacks and those of Hispanic origin probably reflect the relatively younger age distributions for those two groups, compared to non-Hispanic whites, rather than a true lower occurrence of Alzheimer’s.” (Kung, Hoyert, Xu, & Murphy, 2008)

Costs

“People with Alzheimer’s disease and other dementias are high users of healthcare and long-term care services.” (Alzheimer's Association, 2009) They incur more than three times the number of hospital stays as other older people. Correspondingly, stays in skilled nursing facilities and home health care expenses add to mounting costs. Coexisting medical conditions such as coronary heart disease, diabetes, congestive heart failure and cancer exacerbate the problem. In 2004, per-person payments from all sources for health and long-term care were three times higher for Medicare recipients aged 65 and older with AD and other dementias than others in that same group without these conditions. These facts equated to $33,007 per person compared to $10,603 per person. (Bynum, 2009)

What were the total financial costs for AD and other dementias in the United States in 2005? The Alzheimer's Association estimated the expenditures were $148 billion. Direct medical costs (i.e. medication and general health care) accounted for $112 billion of this amount. The Medicare portion for care of beneficiaries was $91 billion. State and federal Medicaid costs for nursing home care equaled $21 billion. Indirect costs to businesses were estimated at $36.5 billion for employees who were caregivers. This tally included reduced hours, time off, or employees leaving their jobs because of the demands of providing care.

Future Facts

The "Baby Boomer" retirement population will have a major impact on the economy and infrastructure in the United States. The first wave will turn 65 in 2011 and all will be at least 65 years old by 2029. What does this mean in raw numbers? New AD cases per year will be 615,000 in 2029 and 959,000 in 2050, at which time there will likely be 11 to 16 million people 65 or older with the disease. More than 60% will be 85 or older. Currently 2.7 million people in this age group live with AD, with a projection of 3.5 million as the first wave of "Baby Boomers" reaches 85 years in 2031. (Alzheimer's Association, 2009)

Shifting the Paradigm from Traditional Healthcare to Telehealth

Overview

As alluded to in the previous section, healthcare is a burgeoning field poised to develop exponentially as "Baby Boomers" ready for retirement. It is questionable whether the current brick-and-mortar infrastructure is realistically equipped to provide sufficient quality care to the aging population and all others concomitantly affected by this group's impact. Over the past several decades, industry, academia and governmental experts have been devising a solution that aspires to complement the traditional system. Personal telehealth, of which cognitive health coaching is an element, can potentially revolutionize healthcare while fostering independence and retention of dignity among its ultimate beneficiaries.

Background of Telehealth

Definition of Telehealth

Telemedicine and telehealth are terms often used interchangeably. Bashshur and colleagues provide a concise definition (Bashshur, Sanders, & Shannon, 1997):

> "Telemedicine involves the use of modern information technology, especially two-way interactive audio/video communications, computers and telemetry to deliver health services to remote patients and to facilitate information exchange between primary care physicians and specialists at some distance from each other."

Continuous advances in computer, electronics, and communications technologies are paving the way for enhanced healthcare opportunities on a remote basis. Processing power is continuously increasing and electronic devices are becoming smaller and extremely sophisticated. Wired and wireless mediums are now in the hundreds of megabits per second (Mbps) to gigabits per second (Gbps) range, allowing for real-time communications without suffering from packet latency complications. The ubiquity of such tools and a more technically educated world add to the efficacy of personal telehealth, which extends to a home environment.

History in the United States

Telehealth was an idea conceived by healthcare technology leaders in the United States during the 1960s. (Kazal & Conner, 2005) The original notion was to promote health care provider coordination and education, particularly for those serving in rural areas. Cost-effectiveness and quality of care were also deemed top priorities for this initiative. Times have changed but these core competencies remain at the heart of establishing a sustainable system.

Telehealth Safety Benefits

Reactive Treatment

Gareth Williams (Williams, 2004) discusses some existing healthcare issues and how personal telehealth could help to alleviate them. One prominent factor attributing to reduced patient safety is the reactive nature of contemporary treatment. Symptomatic patients must typically present themselves and their condition before a medical professional in order to be diagnosed and treated. A host of limiting factors exists to hamper prompt care: personal mobility, public or private transportation, remote rural location, availability of appropriate medical professionals, ability to effectively communicate, etc. Time can be the crucial difference between life and death in some cases.

Personal telehealth will attempt to shift the paradigm 180 degrees toward a proactive approach. Home monitoring enables treatment administration immediately after discovering a problem. Medical professionals can directly contact the patient via telephone or interactive video communication to recommend medication or other interventions. Additional healthcare providers (e.g. physical therapists) can be concurrently notified and activated if necessitated.

Memory Concerns

Patients with conditions that decrease memory acuity, such as AD and other forms of dementia, can be at serious risk. They often forget to take prescribed medications or perform routine periodic tests. Failure to adhere may lead to dire consequences. Personal telehealth affords a solution through electronic alerts or reminders when the remote human monitor (e.g. cognitive health coach) sees activities have not been performed. A patient no longer has to rely upon notes posted on the refrigerator or a clock timer. The latter may sound an alarm but a person with memory impairment may not remember why he set it.

Inactivity or Disorientation

Certain chronic maladies may render a patient inactive or disoriented. Sudden onset of stroke effects or extreme lethargy experienced from other conditions may suddenly leave someone bedridden. There are many news accounts of a loved one venturing off somewhere and forgetting her name and address due to temporary disorientation or short-term memory loss. The disorientation could even manifest within the confines of one's own home.

Personal telehealth proposes activity and location tracking as methods to mitigate safety concerns. Wireless Local Area Network (LAN) technologies (e.g. Wi-Fi®) have the ability to utilize access points for location approximation. Global Positioning System (GPS) signals and broadband wireless, such as WiMAX, also offer means to identify and track patients. Existing privacy laws may restrict promulgation of this technology until opponents can be convinced of the benefits. However, it is fairly easy to digest the notion of tracking if use is limited to cases where inevitable harm to certain individuals could result.

Telehealth Cost Benefits

Prolonged Hospital Stays

One of the cost issues Williams imparts is unnecessary or prolonged hospital stays, most notably for patients who have undergone surgery. (Williams, 2004) Average daily expenses range depending upon the condition but can easily amount to many thousands of dollars. Medical staff may err on the side of caution to ensure a more successful recovery. However, the tendency to overestimate personal monitoring time is always a possibility. Home monitoring systems can be employed to reduce overall hospital expenditures and free up a much-needed bed for someone in a more critical situation.

Constant Monitoring at a Facility

Constant monitoring and attention at a hospital or other care facility are not always warranted for many patients. These tasks consume valuable time and other resources that translate into substantial financial sums. The idea of automating monitoring procedures is closely related to the reactive treatment issue discussed in the preceding safety section. In the cost context, medical professionals still attack a problem almost immediately after detection but are not burdened by having to sit at a hospital bedside waiting for something to happen. They are only cued to act if an alert is received.

Medical Professionals' Time

Time, most notably its efficient use, is a recurring theme when talking about costs. There exists a large swath of patients who do not need dedicated attention. Those who actually require consideration may be overlooked due to a taxed and inefficient workflow. Personal telehealth can be used to free up medical professionals' time and align patients with specialists, such as cognitive health coaches, better equipped to serve using their unique skills. Patients are effectively triaged; less serious cases are remanded to remote observation in the comfort of their own homes.

Healthcare Technologies

Personal Health Record (PHR) Systems

General PHR Definition

The American Health Information Management Association (AHIMA) defines a PHR as "…a tool that you can use to collect, track and share past and current information about your health or the health of someone in your care." (AHIMA, 2009) The organization makes a distinction between medical records and a PHR. The former contains information about the patient that is compiled and managed by healthcare providers, while a PHR is health information compiled and managed directly by the patient. Each party has a vested interest in maintaining their respective records in order to improve healthcare quality.

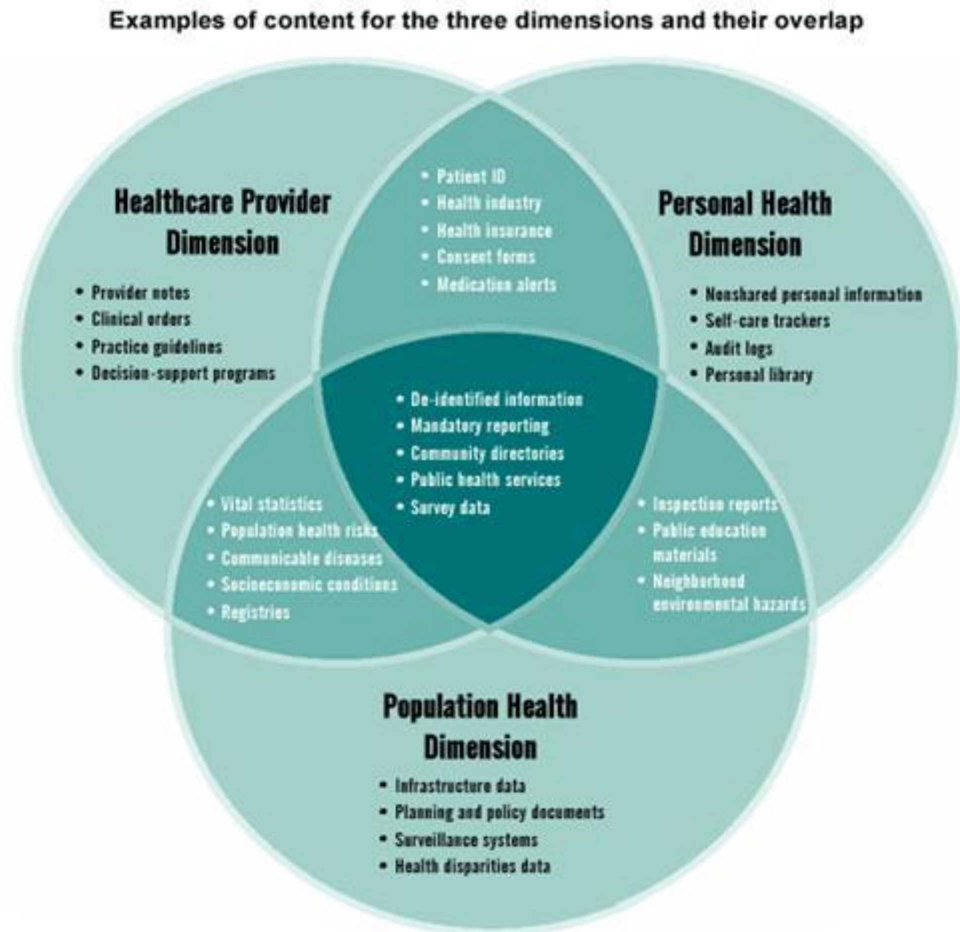
AHIMA lists important points to know about a Personal Health Record:

- You should always have access to your complete health information.
- Information in your PHR should be accurate, reliable, and complete.
- You should have control over how your health information is accessed, used, and disclosed.
- A PHR may be separate from and does not normally replace the legal medical record of any provider.

PHRs as Part of the National Health Information Infrastructure (NHII)

PHRs have the potential to develop far beyond individually maintained personal records. The National Committee on Vital and Health Statistics (NCVHS) produced a report in 2001 that identified three primary areas or dimensions that comprise a NHII. Dr. Simon Cohn, NCVHS Chairman at the time, authored a letter in 2005 to Michael O. Leavitt, Secretary of Health and Human Services. This correspondence described personal health as the area that "…supports individuals in managing their own wellness and healthcare decision making." (Cohn MD MPH, 2005) Further elaboration recognized a more universal goal for the infrastructure to promote optimum information exchange between the three areas: Healthcare Provider Dimension, Population Health Dimension, and Personal Health Dimension.

Figure 1: National Health Information Infrastructure Dimensions



(Cohn MD MPH, 2005)

Dr. Cohn's letter listed many PHR system potential benefits identified by NCVHS. For example, consumers, patients, and their caregivers could improve their understanding of health issues, increase their sense of control over health, and support home monitoring for chronic diseases. Healthcare providers might improve access to data from other providers and the patients themselves, improve medication compliance, and improve documentation of communication with patients. Also, payers could benefit through improved customer service, information and education to beneficiaries, and enhanced wellness and preventative care.

Table 1: Key Potential Benefits of PHRs and PHR Systems

Key Potential Benefits of PHRs and PHR Systems	
Roles	**Benefits**
Consumers, Patients and their Caregivers	• Support wellness activities • Improve understanding of health issues • Increase sense of control over health • Increase control over access to personal health information • Support timely, appropriate preventive services • Support healthcare decisions and responsibility for care • Strengthen communication with providers • Verify accuracy of information in provider records • Support home monitoring for chronic diseases • Support understanding and appropriate use of medications • Support continuity of care across time and providers • Manage insurance benefits and claims • Avoid duplicate tests • Reduce adverse drug interactions and allergic reactions • Reduce hassle through online appointment scheduling and prescription refills • Increase access to providers via e-visits
Healthcare Providers	• Improve access to data from other providers and the patients themselves • Increase knowledge of potential drug interactions and allergies • Avoid duplicate tests • Improve medication compliance • Provide information to patients for both healthcare and patient services purposes • Provide patients with convenient access to specific information or services (e.g., lab results, Rx refills, e-visits) • Improve documentation of communication with patients
Payers	• Improve customer service (transactions and information) • Promote portability of patient information across plan

	• Support wellness and preventive care • Provide information and education to beneficiaries
Employers	• Support wellness and preventive care • Provide convenient service • Improve workforce productivity • Promote empowered healthcare consumers • Use aggregate data to manage employee health
Societal/Population Health Benefits	• Strengthen health promotion and disease prevention • Improve the health of populations • Expand health education opportunities

(Cohn MD MPH, 2005)

Note: This Capstone project explores Microsoft® HealthVault™ and Google™ Health PHR systems. Examples of other vendors, although not an exhaustive directory, can be found at http://www.telemedical.com/Telemedical/personalhealthrecordsystems.html. (Personal Health Record Vendors, 2009)

Electronic Health Record (EHR) Systems

General EHR Definition

Many people have offered varying definitions for an electronic health record (EHR). Tang and McDonald concisely define an EHR as "…a repository of electronically maintained information about an individual's lifetime health status and health care, stored such that it can serve the multiple legitimate users of the record." (Tang & McDonald, 2006) The authors cite some primary benefits of using an EHR, such as accessibility, legibility, completeness, quality, and reusability. These benefits are best realized when information is comprehensive, data use and retention spans an extended period of time, a controlled and predefined vocabulary is utilized, and authorized access is ubiquitous. Conversely, Tang and McDonald point out disadvantages of storing medical records electronically. The most prominent examples are the requirement of a large initial investment in hardware, software, training, and support; the possibility of failures ranging from minor to disastrous; and searching or analyzing a scanned document may require additional software. This last point is largely solved by the advent of the searchable portable document format (PDF).

Ancillary Systems

There are a number of ancillary systems that can work in conjunction with the EHR information repository. A clinical decision support system (CDSS) assists physicians with making logical diagnoses and ordering appropriate interventions. Physicians can override CDSS recommendations but they are usually required to provide feedback as to the decision. Computerized Provider Order Entry (CPOE) systems aid with the delivery of safe, quality healthcare. CPOE presents relevant patient record information at the time of order entry. Intervention alerts (e.g. adverse reaction to medications) and recommendations help prevent potentially life-threatening scenarios.

Two other common systems complement the EHR. Tang and McDonald describe knowledge resources as essential to the completion of a physician's decisions or orders regarding patients. PubMed, OVID, and literature on the National Library of Medicine's search site are instances of information that can be made readily available at the touch of a button. Finally, picture archiving and communication systems (PACS) can prove invaluable relative to effective patient care. PACS stores and retrieves digital images, which may be displayed for review in combination with textual data.

Note: This Capstone project explores the EpicCare® MyChart EMR. Examples of other vendors, although not exhaustive, can be found at http://www.himssehra.org/ASP/members.asp. (HIMSS EHR Association Members, 2009)

Health Data Communications Standards

Overview

Development of healthcare information technology standards is just as important as it is in any other scientific field. Standards provide a common framework for interoperability and communication between disparate systems. Vendors can retain control over core hardware and software intellectual property, while enabling underlying protocols to transparently propagate data. This concept is no less critical in biomedical informatics, and pertinent to this paper's aim of integrating health monitoring and behavioral data into PHRs and EHRs. Although the healthcare industry has been traditionally slow in its adoption of technology, organizations are working to proliferate data standards.

IEEE 11073™ Part 10471

The Institute of Electrical and Electronics Engineers (IEEE) is the "…world's largest professional association advancing innovation and technological excellence for the benefit of humanity." (About IEEE, 2010) IEEE 11073™ is a family of standards for medical device interoperability. Seven Parts were initially adopted on October 1, 2008 (McCabe, 2008):

- 11073-00101 "Health Informatics - Point-of-Care Medical Device Communication - Technical Report - Guidelines for the Use of RF Wireless Technology"
- 11073-10408, "Health Informatics - Personal Health Device Communication - Device Specialization - Thermometer"
- 11073-10415, "Health Informatics - Personal Health Device Communication - Device Specialization - Weighing Scale"
- 11073-10441, "Health Informatics - Personal Health Device Communication - Device Specialization – Cardiovascular Fitness and Activity Monitor"
- 11073-10442, "Health Informatics - Personal Health Device Communication - Device Specialization – Strength Fitness Equipment"
- 11073-10471, "Health Informatics - Personal Health Device Communication - Device Specialization – Independent Living Activity Hub"
- 11073-20601, "Health Informatics - Personal Health Device Communication - Application Profile - Optimized Exchange Protocol"

Part 10471 (Independent Living Activity Hub) most logically pertains to this project. "This standard establishes a normative definition of communication between personal telehealth independent living activity hub devices and compute engines (e.g., cell phones, personal computers, personal health appliances, set top boxes) in a manner that enables plug-and-play interoperability." (IEEE 11073™ Standard Committee, 2008) Since device-device communication resides at the lower layers of the Open Systems Interconnect (OSI) Model, it is out of scope relative to my focus on Layer-7 application communication of data and summarization for PHR/EHR reports. Continuity of Care Document (CCD) and Continuity of Care Record (CCR) formats reside at this upper application layer.

Continuity of Care Document (CCD)

Before discussing CCD, some background information is needed for the Health Level 7 (HL7 – Currently Version 3) Clinical Document Architecture (CDA) standard. "HL7 provides standards for interoperability that improve care delivery, optimize workflow, reduce ambiguity and enhance knowledge transfer among all of our stakeholders, including healthcare providers, government agencies, the vendor community, fellow SDOs and patients." (About HL7, 2010) CDA Release 2.0 distinctively provides an exchange model for clinical documents (i.e. discharge summaries and progress notes) and strives to perpetuate the universal implementation of EHRs in the healthcare industry. CDA leverages XML, the HL7 Reference Information Model (RIM), and coded vocabularies to make documents machine-readable and human-readable. (Clinical Document Architecture, 2010)

CCD is a subset of the HL7 CDA. It is a collaboration effort between the HL7 CDA and the American Society for Testing and Materials (ASTM) International Continuity of Care Record (CCR) specification that will be discussed in the next section. CCD maps CCR data elements into a CDA representation. (Alschuler, 2006) Some CCD benefits from Alschuler's presentation are listed below. A Wikipedia definition provides an additional, simplified summary: "CCD is an XML-based markup standard intended to specify the encoding, structure and semantics of a patient summary clinical document for exchange." (Continuity of Care Document, 2009)

CCD Benefits:

- Industry consensus on summary document contents and requirements through ASTM ballots (2004, 2005)
- Industry consensus on document exchange framework through HL7 ballots (1999-2005)
- Summaries for continuity of care
    - Interoperable with full range of document types
    - Interoperable with HL7 V3 messages, all RIM-based specifications (public health reporting, clinical trials, structured product labels and more)

CCR (ASTM International Standard)

ASTM International developed the E2369 Standard Specification for Continuity of Care Record (CCR) specification. "CCR is a core data set of the most relevant administrative, demographic, and clinical information facts about a patient's healthcare, covering one or more healthcare encounters." (ASTM Subcommittee E31.25, 2010). It provides a format for assembling all of the pertinent data about a patient and forwarding it to another entity to support the continuity of care. CCR is based on XML coding that is required when the CCR is created in a structured electronic format. Security and privacy is maintained by allowing only properly authenticated and authorized access to the CCR document instance or its elements. The CCR consists of three core components: the CCR Header, the CCR Body, and the CCR Footer.

Note: Google™ Health supports a subset of CCR (Google Health Data API CCR Reference, 2010) and Microsoft® HealthVault™ supports subsets of both CCR and CCD. (Microsoft Video: Using CCR & CCD with HealthVault , 2009)

SNOMED Clinical Terms® and LOINC Codes

Additional Systematized Nomenclature of Medicine Clinical Terms® (SNOMED CT®) and Logical Observation Identifiers Names and Codes® (LOINC®) may need to be developed for the new, unique cognitive and behavioral summary metrics variables and results developed in this study. These new codes might become necessary in CCD message templates as depicted in this paper's Proposed HL7 CCD Message Format example.

“SNOMED CT® is a comprehensive clinical terminology, originally created by the College of American Pathologists (CAP) and, as of April 2007, owned, maintained, and distributed by the International Health Terminology Standards Development Organisation (IHTSDO), a non-for-profit association in Denmark. The NLM is the U.S. Member of the IHTSDO and, as such, distributes SNOMED CT at no cost in accordance with the Member rights and responsibilities outlined in the IHTSDO's Articles.

SNOMED CT is one of a suite of designated standards for use in U.S. Federal Government systems for the electronic exchange of clinical health information and is also a required standard in interoperability specifications of the U.S. Healthcare Information Technology Standards Panel. SNOMED CT is also being implemented internationally as a standard within other IHTSDO Member countries.” (Unified Medical Language System®, 2009)

“The purpose of LOINC® is to facilitate the exchange and pooling of clinical results for clinical care, outcomes management, and research by providing a set of universal codes and names to identify laboratory and other clinical observations. The Regenstrief Institute, Inc., an internationally renowned healthcare and informatics research organization, maintains the LOINC database and supporting documentation, and the RELMA mapping program.” (Logical Observation Identifiers Names and Codes (LOINC®), 2010)

OHSU Cognitive Health Coaching Project

Phase 1

In 2007 Oregon Health & Science University (OHSU) and the Oregon Center for Aging & Technology (ORCATECH) began collaborating on a project to develop a "…software architecture and methodology for monitoring cognitive performance using data from a suite of computer games and for providing automated tailored feedback for cognitive health coaching" in a home environment. (Jimison & Pavel, 2007) The goal was to study the use of health coaches to assist the elderly in improving health behaviors, which would be a less expensive approach than traditional clinicians working with patients in an office setting. This project consisted of cognitive computer games used for monitoring progress and providing specific and adaptive cognitive exercises for individuals. The coaching application included involvement from the patient, family caregiver, and health coach.

Phase 2

Phase two commenced in late 2009 with the goal of developing and testing the "feasibility of a cognitive intervention for elderly adults that is low-cost, multi-faceted, sustainable, and effective." (Jimison, 2009) This ongoing study employs an expert system with adaptive algorithms for creating a dynamic tailored action plan for cognitive health for each participant. The cognitive health action plan calls for monitoring new observations of daily living (ODLs): cognitive metrics from the adaptive computer games; sleep quality from bed mat sensors; socialization metrics from Skype™, email, and phone use; and activity and medication adherence. A health coach communicates with participants via a Web-based software platform in order to deliver cognitive intervention based on tailored recommendations for cognitive computer games, novelty exercises, physical exercise, socialization, and sleep management. The main goal of this project is to expand capabilities of the Web-based cognitive health coaching system in the home, and transfer summary data from the coaching database to a PHR and EHR for broader dissemination.

Home Health Monitoring Wellness and Disease Management

Dr. Holly Jimison's OHSU phase two cognitive health coaching project also investigates disease management and wellness. The team interviewed a variety of experts and stakeholders who would have had an interest in this new approach to home health management for elders. Stakeholders included government legislators and policymakers, geriatricians, industry representative, researchers, senior housing specialists, home health nurses, and senior activities directors. (Jimison, 2009)

The need for integration of systems and workflow were recurring feedback themes. Most pointedly, disease management systems handle only one chronic condition at a time, while most elders have at least two chronic conditions. Multiple computer systems for patient care hamper coordinated care and create increasingly difficult workflow issues. Many responses revolved around the use of federally supported interoperability standards and certified products. Scalability and economic feasibility of this project relies upon seamless integration with other electronic data sources and compatibility with current clinical and home health workflow. As a last note, the disease management experts added that "Current disease management systems do not explicitly incorporate health behavior change principles, such as making use of readiness-to-change stage assessment or motivational interviewing techniques."

Related Work

The Continua® Health Alliance, a consortium of healthcare and technology companies collaborating to improve the quality of personal healthcare through interoperable solutions (About the Alliance, 2009), has been working on a Personal Healthcare Monitoring (PHM) Reports project that was approved September 2007. (HL7, 2008) The Continua® V1 XHR Interface proposes to link disease management service providers, healthcare practitioners, and data collection device data (i.e. phone calls, face to face, patient data entry, Continua® device data). The project's intended users are: 1) PHM organizations to transfer patient disease management data to EHRs; and 2) Future extensions for Health & Fitness and Living Independently data. It is based on the draft ISO/IEEE 11073 standard for HL7 v3 RIM CDA Release 2. SNOMED codes, LOINC codes, and HL7 OIDs are included in the proposal.

Research Question and Specific Aims

Research Question

What is the best way to take new home monitoring and behavioral data, and summarize them for representation into a personal health record and electronic health record?

Specific Aims

I. The first aim is to define the new monitoring and behavioral summary metrics variables, and their respective elements. The foremost three items listed below are primary variables of interest for this study; they are emboldened for emphasis. I will also attempt to present the constituent data elements as proposed HL7 Continuity of Care Document (CCD) message formats based on existing standards for other measures.

   a. **Sleep management: I will use data from bed mats and load sensors for assessing quality of sleep. The goal is to report on sleep activity to detect whether there are any abnormal patterns that should be addressed by health coaches or clinicians.**

   b. **Cognitive monitoring and remediation: I will use data from the suite of cognitive computer games developed by the OHSU team. Additional metrics consist of monitoring trigrams, passwords, application focus events, login events, and mouse data. The eventual goal is to report on these memory metrics by summarizing their significance relative to daily values and variability of memory, divided attention, planning, verbal fluency, motor skills, etc.**

c. **Socialization: I will use data from subject personal computers that record interactions. Media include email, phone, and Skype™ audio/video/chat sessions. The goal is to report on the level of social engagement to determine if subjects have isolated themselves.**
d. Physical exercise using motion sensors
e. Medication adherence using Bluetooth® medication tracking devices
f. Diet and weight management
g. Readiness to change (very infrequent): This variable includes motivational interviewing, and health behavior change (trans-theoretical): contemplative, action, maintenance, etc.
h. Self-efficacy (very infrequent): This variable measures a person's confidence in carrying out a behavior in a new area and adhering to a plan. An example is the ability to abstain from television prior to sleeping.

II. The second aim is to research PHR systems to develop standardized summaries of data from the three key variables. I would like to understand what features and tools PHR systems offer consumers, and their health coaches, who are monitoring their own health via the Web. The idea is to provide a meaningful report that summarizes data rather than listing many individual measurements for a period of time. For example, the PHR might present an average of cognitive game scores for a given time period and illustrate the trend with a graph. Health coaches could then assess whether or not a patient is improving in certain areas.

III. The third aim is to consult with OHSU staff to understand which summary reports from the PHR might be relevant and useful to clinicians using EHR systems. Ultimately, clinicians, health coaches, and family members could work together to create tailored health action plans for the patient.

Methods

Pre-Assessment

An in-person interview was conducted with Rick Cnossen on February 25, 2010, to glean background information on Personal Healthcare Monitoring Reports (PHMR) and standards developed by IEEE® and the Continua® Health Alliance. Mr. Cnossen is the Continua® Health Alliance President and Chair of the Board of Directors. He is also the Director of Personal Health Enabling within the Intel Digital Health Group.

Raw Data Collection

This study used data collected from the ongoing OHSU health coaching project that recruited participants from the Oregon Center for Aging & Technology (ORCATECH) Living Lab. The following Living Lab information is an excerpt from Dr. Holly Jimison's project proposal (Jimison, 2009). It provides a brief overview of core monitoring technologies, subject testing, and study design.

Overview

ORCATECH is a group of seniors who have agreed to have unobtrusive monitoring technologies installed permanently in their homes. This lab was established in 2006 to provide a test-bed for evaluating behavioral monitoring technology. The Living Lab seniors live in diverse home environments within the community, ranging from large single-family dwellings to studio apartments in retirement communities. Each of these seniors has had some or all of the existing ORCATECH technology suites installed in their homes.

Core Technologies

- Motion sensors (X10 MS16a)
- Door sensors (X10 DS10A)
- Bluetooth medication tracking device
- Home computer, from which daily use measures are taken (time spent in email, web surfing, word processing)
- Cognitive Computer Games (cognitive measures derived from computer interactions during game play
- Phone sensor for detecting incoming and outgoing calls (USB)
- Bed mats and/or load cells in some homes for assessing restlessness and activity in bed (USB)

Testing

These seniors undergo an extensive series of neuropsychological and clinical tests, including the assessments that make up the Uniform Data Set used by the National Institutes of Health (NIH)-funded Alzheimer's Disease Centers. In addition, the characteristics of their home environment (type of home, home construction materials, number of rooms, etc.), and of their socialization habits (regular outings and visitors) are documented. Every subject also completes a short weekly online questionnaire.

Study Design

There are 34 participants (22 female, 12 male) with an average age of 76.1 ± 4.9 years. They have been monitored, on average, more than 300 days. House sizes range from three to 16 rooms (average 9.0 ± 3.7), and home construction materials include steel frame, wood frame, and concrete. In addition to having the base technologies installed in their homes, to date the participants have consented to participate in seven (7) specific studies of technology, ranging from participating in focus groups to the installation and/or use of additional monitoring technologies.

These volunteers have been the participants in OHSU health coaching studies thus far. They have tested various medication reminding systems, various sleep mat sensors, activity monitoring, etc. In addition, the OHSU team has been able to pilot its ability to collect monitoring data from the homes, transfer it nightly to a secure server at OHSU, store useful summarizations in their database, and generate tailored coaching messages based on protocol algorithms. The cognitive health coaching team recruited participants from this subject pool, expecting that additional subjects would be added to the ORCATECH Living Lab.

Define the New Monitoring and Behavioral Summary Metrics Variables

Overview

The cognitive health coaching metrics variables and their respective data elements had to be thoroughly defined before this study could proceed. This process step entailed contacting team members responsible for compiling data from various tests. Depending on the variable, raw data extraction methods ranged from direct database queries to MATLAB® scripts that generate results and export them to a database table each night. The team member who supplied the data also provided brief descriptions of each element and its appropriate unit of measure, if applicable. Elaboration required research on various database pages within the ORCATECH Wiki site. (ORCATECH Wiki, 2010)

The next step in the current study was to clarify these descriptions for the benefit of stakeholders unfamiliar with project minutiae. The variables were categorized into three main groups: sleep management, cognitive monitoring and remediation, and socialization. Sleep management was assessed using bed mat sensors. Cognitive monitoring and remediation testing consisted of computer games and monitoring of trigrams, passwords, application focus events, login events, and mouse data. Finally, socialization included telephone monitoring and Skype™ usage metrics.

Some data formats were not easily recognized or translatable by the human observer. An example would be the sleep Day element. The date string was in the MATLAB® ‘datenum’ format (e.g., 1/1/1970 + the value appeared as 733960). This general problem was rectified when the MATLAB® script was converted to PERL for nightly processing.

Details for Translation to CCD Format

A new CCD template will be needed in order to transmit data between the majority of existing PHR and EHR systems. Constituent sleep management data elements were drafted into a proposed HL7 Continuity of Care Document (CCD) message body format, based on existing HL7 CCD templates for other measures found in the HL7 Implementation Guide for CDA Release 2.0. (HL7, 2008) This draft standard for trial use (DSTU) describes constraints on the CDA Header and Body elements for Personal Healthcare Monitoring Report (PHMR) documents. Information is transmitted as notes and as raw data, with any of the following characteristics:

- Representation of measurements captured by devices.
- Representation of notes, summaries, and other kinds of narrative information that may be added by caregivers or by the users themselves.
- Representation of graphs that may be added by intermediary devices that represent trends of users' health.

The focus in this study was on General Body Constraints and the Results section. Header Constraints contain standard information relevant to the document itself (e.g., languageCode) and its participants (e.g., dataEnterer). Also, the Results section is required when there is no Vital Signs section, which was the case in this study. Therefore, Header Constraints and a Vital Signs section were not mentioned further. Documentation supporting these decisions is supplied in the following paragraphs.

Referring again to General Body Constraints, the referenced DSTU (HL7, 2008) specifies:

> **CONF-PHMR-43:** A Personal Healthcare Monitoring Report **SHALL** have a structuredBody element. The content of this element makes up the human-readable text of the document. This information **SHALL** be organized into sections and **MAY** have subsections.
>
> **CONF-PHMR-44:** Except where specifically noted in this DSTU, the structured body of a Personal Healthcare Monitoring Report **SHALL** conform to the constraints of HL7's Continuity of Care Document (CCD) specification (published April 1, 2007), and all references to CCD templateIds apply to that initial release of CCD.

Required Section: Results 30954-2 (HL7, 2008)

The results section is only required if there is no Vital Signs section.

> **CONF-PHMR-57:** A Results section **SHALL** contain two templateIds. CCD templateId 2.16.840.1.113883.10.20.1.14 **SHALL** be present and the section **SHALL** conform to all the constraints specified in CCD for that template. An additional templateId **SHALL** be present where the value of @root is 2.16.840.1.113883.10.20.9.14, indicating conformance to the constraints specified in this DSTU.
>
> **CONF-PHMR-58:** One or more Numeric Observations (templateId 2.16.840.1.113883.10.20.9.8) **SHOULD** be present inside entry elements.

CONF-PHMR-59: One or more Waveform Series Observations (templateId 2.16.840.1.113883.10.20.9.12) **MAY** be present inside entry elements.

CONF-PHMR-60: If no results are recorded, this section **SHALL** contain a text element noting this fact.

Table 2: Common Object Identifiers (OIDs)

Code System	**Object Identifier (OID)**
IEEE 11073 (aka MDC)	2.16.840.1.113883.6.24
SNOMED CT®	2.16.840.1.113883.6.96
LOINC®	2.16.840.1.113883.6.1
EUI-64	2.16.840.1.113883.6.24
GMDN	2.16.840.1.113883.6.276

Research PHR Systems to Develop Standardized Summaries

Developing standardized variable summaries required researching Microsoft® HealthVault™ and Google® Health PHR systems via their respective Web sites. Firstly, compatible devices, health and fitness partner sites, and development tools were described. Then a test account was created on each PHR system. This step provided a look into measurements and representation of results, site features, and navigation. Based on these findings, Microsoft® Excel and SPSS® statistical analysis software summaries were generated for select tests in each of the three main study categories: sleep management, cognitive monitoring and remediation, and socialization. Summary formats included tables, graphs, and dashboards. Some sample reports, citing the sleep management variable, were already created through previous work by the team.

Consult with OHSU Staff to Develop Summary Reports

Proposed PHR summary reports were carried forward to this section for presentation to OHSU staff members and grant researchers. A ninety-minute information gathering ("brainstorming") session was conducted with these personnel on May 5, 2010. Additional feedback was subsequently gleaned from some individuals via emails and an individual interview. Finally, supplementary data analysis was conducted in the master spreadsheet document in an effort to derive EHR summary reports from the PHR examples and input from OHSU staff and researchers.

Results

A mixed research methodology was used to obtain meaningful project results. It was composed of traditional information gathering techniques, personal interviews, and review of PHR and EHR systems. Resultant findings indicated dashboard, graph and chart formats should be employed and catered to the respective summary reporting preferences of health coaches and clinicians. Sample reports were made available to the cognitive health coaching team for future implementation into a test or production infrastructure.

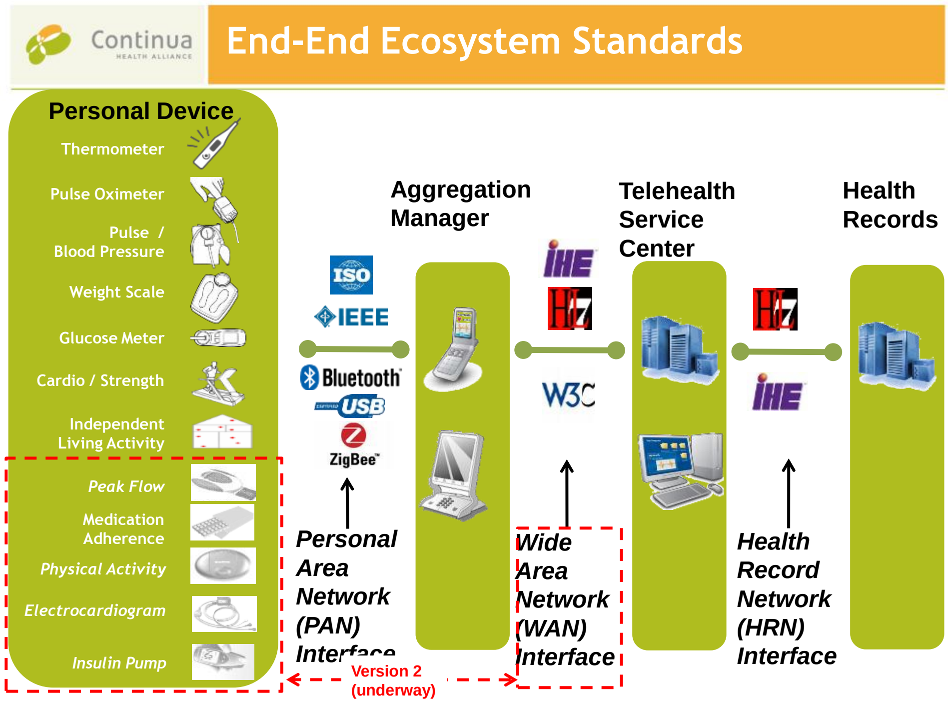
Pre-Assessment

Interview with Rick Cnossen

An in-person interview was conducted with Rick Cnossen on February 25, 2010, to glean background information on HL7 Personal Healthcare Monitoring Reports (PHMR) and standards developed by IEEE and Continua. (Cnossen, 2010) Mr. Cnossen is the Continua® Health Alliance President and Chair of the Board of Directors. He is also the Director of Personal Health Enabling within the Intel Digital Health Group.

Mr. Cnossen shared a presentation illustrating the PHMR End-End Ecosystem from a CommNexus meeting held in early 2010. The graphic depicts components starting at the personal device end of the spectrum and flowing through the final health record. Various standards and interfaces exist at each stage. Mr. Cnossen also provided some contacts he thought might be useful sources of information.

Figure 2: PHMR End-End Ecosystem Standards



(Cnossen, President & Board Chair, Continua Health Alliance®, 2010)

Items of particular interest noted by Mr. Cnossen:

- IEEE 11073 – Part 20601 is the main framework document from which the various parts draw their information. IEEE 11073 - Part 10471 (Device specialization—Independent living activity hub) is the specific standard that cognitive and behavioral summary reports should be predicated upon when integrating them into PHRs and EHRs.
- Google™ Health is rethinking its PHR strategy and may adopt CCD. Mr. Cnossen confirmed Microsoft® HealthVault™ supports both CCD and CCR.

- The interviewee provided a document detailing IEEE to CCD mapping templates. (Continua® Health Alliance, 2009) A template example is briefly presented in the definitions section that follows this interview.
- There are standardized APIs to map Continua® Health Alliance product data to PHRs and EHRs. Lamprey Networks and IBM are companies that provide such services. They are noted in the Appendices.
- Barriers and challenges: interoperability standards (Continua® Health Alliance), business models, clinician acceptance (workflow, data overload), Regulatory and liability, security and privacy (identifiers), quality (coverage, bandwidth), and international solutions. (Cnossen, President & Board Chair, Continua Health Alliance®, 2010)
- Success stories: The interviewee mentioned Darkins' 2008 paper. (Cnossen, President & Board Chair, Continua Health Alliance®, 2010) Details of Dr. Adam Darkins statement to the House Committee on Veterans Affairs elucidate the study. (Darkins, 2009) Essentially, the Department of Veterans' Affairs (VA) provided real-time video-conferencing to 34,000 veterans in rural areas. Most of the services involved treatment of mental health conditions. Some noteworthy results included a 19.74% decrease in hospital admissions and a 25.31% reduction in bed days of care.

Mr. Cnossen's input provided the background necessary to better understand HL7 PHMRs and standards developed by IEEE and Continua. His PHMR End-End Ecosystem graphic illustrated components ranging from personal devices to the final health record. These concepts are the underlying framework for constructing summary reports. Furthermore, the discussion of barriers and challenges shed light on what adversities must be addressed and overcome.

Defining New Monitoring & Behavioral Summary Metrics Variables

The cognitive health coaching metrics variables and their respective data elements had to be thoroughly defined before this study could proceed. This process step entailed contacting team members responsible for compiling data from various tests. Descriptions were clarified for the benefit of stakeholders unfamiliar with project minutiae. The variables were categorized into three main groups: sleep management, cognitive monitoring and remediation, and socialization. Sleep management was assessed using bed mat sensors. Cognitive monitoring and remediation testing consisted of computer games and monitoring of trigrams, passwords, application focus events, login events, and mouse data. Finally, socialization included telephone monitoring and Skype™ usage metrics.

Sleep Management

Bed mat sleep sensor data comprises the main and only variable for the sleep management monitoring category. Raw sample data was collected from one participant as an example. The entire set consists of 101 days of measurements. Analyses and proposed summary data will be featured in the subsequent PHR and EHR collaboration sections. Data definitions are elucidated and a proposed HL7 CCD Message Format example is included for future project iterations.

Table 3: Sample Sleep Management Raw Data

Day	BedTime	RiseTime	Initial Sleep Latency	Time In Bed	Time Out of Bed	Trips Out of bed	Trips to Bathroom	Restlessness	Total Sleep Latency	Trips to Kitchen
733585	0.9294	1.2476	13.38	7.59	3.00	2.00	2.00	0.53	24.07	0.00
733586	0.9294	1.2463	23.57	7.52	5.00	2.00	2.00	0.66	24.97	0.00
733587	0.8963	1.2289	0.00	5.67	138.83	3.00	3.00	1.94	29.10	0.00
733588	0.9058	1.2476	19.93	8.13	4.33	3.00	3.00	1.11	53.12	0.00
733589	0.8906	1.2395	0.12	8.33	2.58	2.00	2.00	0.24	0.42	0.00
733590	0.9239	1.2490	33.15	7.70	6.08	4.00	4.00	0.78	33.42	1.00
733591	0.9295	1.2512	6.48	7.56	9.67	4.00	3.00	1.32	46.42	1.00
733592	0.9087	1.2565	1.28	8.19	9.33	3.00	3.00	0.61	1.40	0.00
733593	0.9278	1.2520	0.13	7.75	2.00	1.00	1.00	0.65	0.27	0.00
733594	0.9189	1.2545	1.15	8.00	3.42	2.00	2.00	0.13	1.15	0.00
733595	0.9294	1.2399	0.60	7.40	3.17	2.00	2.00	0.00	0.60	0.00
733596	0.9181	1.2562	0.47	8.04	4.83	3.00	3.00	0.12	0.62	0.00
733597	0.8985	1.2352	0.00	7.78	18.25	4.00	4.00	0.90	0.23	0.00
733598	0.9063	1.2351	0.30	7.27	37.50	3.00	3.00	1.10	0.63	1.00
733599	0.9351	1.2481	0.33	7.46	3.58	2.00	2.00	0.13	0.45	0.00
733600	0.9218	1.2499	0.23	7.81	4.08	3.00	3.00	1.15	0.60	0.00
733601	0.9551	1.2535	0.12	7.05	7.00	2.00	2.00	0.99	8.35	0.00
733602	0.9261	1.2279	0.00	7.13	7.17	3.00	3.00	1.26	35.10	1.00
733603	0.9083	1.2440	5.93	7.98	4.50	3.00	3.00	0.38	5.93	0.00

Nicole Larimer, Cognitive Health Coaching Project Manager, provided key data needed to formulate the following synopsis. She gave a brief description of each element and its appropriate unit of measure, if applicable. For the purpose of clarifying data elements in this study, more detailed definitions were drafted.

Table 4: Sleep Management Data Element Definitions

Data Element	***Units***	***Definition***
Day	Days	Day of Year: MATLAB® 'datenum' format (e.g., 1/1/1970 + the value appears as 733960) is converted to 'mmddyy' for processing to the database through the use of a PERL script.
BedTime	1 Day	Time at which the study participant first attempts to go to bed. The element is displayed in decimal format, as a percentage of a 24-hour day, but is converted to a standard time format through the use of a PERL script.
RiseTime	1 Day	Time at which the study participant wakes up for the rest of the day. The element is displayed in decimal format, as a percentage of a 24-hour day, but is converted to a standard time format through the use of a PERL script.

Data Element	***Units***	***Definition***
Initial Sleep Latency	Minutes	Time between when the participant enters the room (bedroom sensor fires) and when he/she falls asleep The term is also referred to as acquiescence because this is the period required for the body to condition itself for sleep.
Time In Bed	Hours	This value is calculated using the following formula: (RiseTime - BedTime) - (Time Out of Bed + Initial Sleep Latency).
Time Out of Bed	Minutes	Total time spent out of bed between periods of being in bed
Trips Out of bed	N/A	Number of trips out of bed between periods of being in bed. Reasons for getting out of bed include trips to the bathroom and kitchen.
Trips to Bathroom	N/A	Number of trips out of bed for visiting the bathroom.
Restlessness	Firings of Sensor/Hour	Bedroom firings per hour spent in bed starting after the first instance of acquiescence to getting up.
Total Sleep Latency	Minutes	Aggregate Sleep Latency for all trips out of bed for that night.
Trips to Kitchen	N/A	Number of trips out of bed for visiting the bathroom.

Figure 3: Proposed HL7 CCD Message Format - Sleep Management Results Section Example

```
NOTE: Template ID, Object IDs and root numbers are taken from the Glucose Meter Results template example in the CDA guide. (HL7, 2008)  It may become necessary to add codes to IEEE 11073, SNOMED CT, LOINC, and other nomenclature sources for the unique variables and results proposed in this study.

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	<templateId root="2.16.840.1.113883.10.20.9.14"/>
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	<text>
		<paragraph>Sleep Management Results</paragraph>
		<table border="1" width="100%">
			<tbody>
				<tr>
					<th>Day</th>
					<th>BedTime</th>
					<th>RiseTime</th>
					<th>Initial Sleep Latency</th>
					<th>Time in Bed</th>
					<th>Time Out of Bed</th>
					<th>Trips to Bathroom</th>
					<th>Restlessness</th>
					<th>Total Sleep Latency</th>
					<th>Trips to Kitchen</th>
				</tr>
				<tr>
					<td>2008/05/01 12:33:33</td>
					<td>22:18:20</td>
					<td>05:56:35</td>
					<td>13.38 minutes</td>
					<td>7.59 hours</td>
					<td>3.00 minutes</td>
					<td>2.00</td>
					<td>2.00</td>
					<td>0.53 sensor firings/hour</td>
					<td>24.07 minutes</td>
					<td>0.00</td>
				</tr>
			</tbody>
		</table>
	</text>
	<entry typeCode="COMP">
```

```
&lt;organizer classCode="CLUSTER" moodCode="EVN"&gt;
&lt;templateId root="2.16.840.1.113883.10.20.1.35"/&gt;
&lt;id root="b606a959-baab-4836-84a8-97c4e9857533"/&gt;
<code code="15220000" codeSystem="2.16.840.1.113883.6.96" displayName="Tests"/>
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&lt;component&gt;
&lt;observation classCode="OBS" moodCode="EVN"&gt;
&lt;templateId root="2.16.840.1.113883.10.20.1.31"/&gt;
&lt;templateId root="2.16.840.1.113883.10.20.9.8"/&gt;
&lt;id root="975c2f3b-2bd4-4e45-aed1-84af9ff51b10"/&gt;
<code code="405176005" codeSystem="2.16.840.1.113883.6.96" codeSystemName="IEEE 11073" displayName="Sleep activity monitoring">
<translation code="MDC_SLEEP_ACTIVITY_MON" codeSystem="2.16.840.1.113883.6.24" codeSystemName="MDC"
displayName="Sleep Activity Monitoring"/>
</code>
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&lt;effectiveBedTime value="221820"/&gt;
&lt;effectiveRiseTime value="055635"/&gt;
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<tripsKitchen= value="0.00"/>
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&lt;/section&gt;
```

One can now better understand the data elements pertaining to bed mat sleep sensor data. For example, Initial Sleep Latency is calculated as the time between when the participant enters the room and when he/she falls asleep. Such terms become important when summarizing data and analyzing for trends. Increasing latency may indicate anxiety or other signs connected with cognitive decline.

Cognitive Monitoring and Remediation

Computer games and monitoring data variables and elements were reviewed in an effort to concisely define them before commencing on PHR or EHR summary work. Understanding these metrics was seen as a crucial step in developing reports that would adequately inform healthcare professionals and other pertinent stakeholders. Sample XML output was also included, which served as a basis for proposed CCD templates. HL7 CCD templates can be developed similar to the sleep management example. Bill Hatt, Cognitive Health Coaching Programmer, provided key data needed to formulate the following synopsis.

Games

All of the games record mouse, keyboard and game state information that enable playback of games in real-time with the researcher dashboard (*optionally installed with games). Simple metrics can be used to create trending graphs. Additional longitudinal metrics will be discussed in the results section.

Existing simple metrics in the game console include:

1. Length of time spent playing each game
2. Number of games played
3. Final score of each game

NOTE: Metrics #2 and #3 are already present in the participant interface.

From a coaching perspective some standard neuropsychological test metrics of interest are (Jimison & Pavel, 2007):

- Verbal fluency: Verbal fluency is the ability to generate a class of words within time constraints. A word jumble game in Letter Lotto is an example where the user is challenged to create as many words as possible from a scrambled set of seven letters. The simple measure of rate of word generation directly corresponds to standard measures of verbal fluency. Complexity measures include estimates of the word entropy as measured by bigram frequencies and word frequency in the English language (greater rare word usage corresponding to higher cognitive function).
- Short-term and working memory: The Concentration game is one test that was used to estimate an individual's memory "buffer length" for both the object (card value) and location (card placement). The team determined maximum and average buffer sizes required for perfect performance. Observed average memory buffer size was then normalized for an individual player to obtain a memory metric.

- Divided attention: The team adapted the Black Jack card game, in which users attempt to place newly dealt cards in locations on the board so they add up to 21 but not over for both rows and columns. The relative performance on rows and columns provided a measure of the user's ability to attend to two tasks at the same time.
- Motor speed and set switching: The Trail Making Test requires subjects to connect a sequence of numbered circles as quickly as possible, and then connect a sequence of alternating numbers and letters (e.g., 1, A, 2, B, 3, C…). This process of set switching (from numbers to letters) requires memory speed and other strengths: memory, visual search, divided attention, and mental flexibility. Standard scores only reflect overall timing and number of errors for this test. For example, measuring an individual subject's speed in following a single highlighted target with the mouse device provides a baseline measure of motor speed, whereas the added time required for alternating sequences reflected additional cognitive load due to set switching.
- Planning and other aspects of executive function: Planning is exemplified by adaptation of the FreeCell version of the Solitaire card game. Efficiency in moving to a solution, as compared with the computer solver, provides a measure of planning.

Table 5: Games Data Element Definitions

Data Element	***Units***	***Definition***
Coaching Data ID	N/A	Category of games (e.g. Cognitive Games) used by health coach. Database field = coaching_dataid
Title	N/A	Game Title: Pyramid Builder is an example. Database field = title
Title ID	N/A	A number (e.g. 1) corresponding to the particular game in the suite of games. Database field = titleid
Game ID	N/A	Number (e.g. 401538) corresponding to the game session for all games. Database field = gameid
Count	N/A	Number of times the game was played in a particular time period (Start Date – End Date). Database field = count
User ID	N/A	A unique identifying number, such as 25001.
Start Date	Date/Time	Calendar date on which a user began playing a particular game or multiple sessions of that game. The measured time period is determined by the health coach. Database field = start_date

Data Element	*Units*	*Definition*
End Date	Date/Time	Calendar date on which a user stopped playing a particular game or multiple sessions of that game. The measured time period is determined by the health coach. Database field = end_date
Game Score	Points	Number of points scored on a particular game. Database field = GAME_SCORE

Example Data for Pyramid Builder (aka TitleId #1):

<coaching_data id="Cognitive Games" title="Pyramid Builder" titleid="1" count="11" userid="25001" start_date="2009-09-14" end_date="2010-02-17">

<entry>

<gameid>401538</gameid>

<titleid>1</titleid>

<dttm>2009-09-14-19-29</dttm>

<GAME_RESULT>4</GAME_RESULT>

<GAME_SCORE>120</GAME_SCORE>

</entry>

<entry>

<gameid>401539</gameid>

<titleid>1</titleid>

<dttm>2009-09-14-19-33</dttm>

<GAME_RESULT>4</GAME_RESULT>

<GAME_SCORE>210</GAME_SCORE>

</entry>

<entry>

<gameid>427497</gameid>

<titleid>1</titleid>

<dttm>2009-12-12-02-02</dttm>

<GAME_RESULT>4</GAME_RESULT>

<GAME_SCORE>310</GAME_SCORE>

</entry>

<entry>

<gameid>428233</gameid>

<titleid>1</titleid>

<dttm>2009-12-14-20-27</dttm>

<GAME_RESULT>4</GAME_RESULT>

<GAME_SCORE>20</GAME_SCORE>

</entry>

<coaching_data>

Adaptive cognitive games are an important means of evaluating cognitive functioning. Verbal fluency, short-term and working memory, divided attention, motor speed, and planning and other aspects of executive function are intertwined with the mix of games in this study. Key data elements include the length of time spent playing each game, number of games played, and the final scores of each game. Trending can be analyzed to developed individual care plans.

Computer Monitoring

Computerized monitoring of trigrams, passwords, application focus events, login events, and mouse data also assist cognitive health coaches assess the status of participants' health. One interesting metric is the total amount of time spent on the computer during each computing session. The algorithms used in generating this metric are complete and are being validated for accuracy. Typing speed in password and trigram data is another metric of value. Finally, linguistic complexity trigram data provides health coaches with insight regarding cognitive development or decay.

Table 6: Sample Computer Usage Raw Data

BRP_ID	Date	Start Time (HH:MM)	Duration
999	11/16/2007	16:52	1606.329
999	1/22/2008	22:12	1391.003
999	1/30/2008	12:43	491.09
999	1/31/2008	9:18	1164.928
999	1/31/2008	12:18	769.189
999	1/31/2008	17:21	206.764
999	2/5/2008	11:21	939.271
999	2/5/2008	14:50	1292.882
999	2/5/2008	20:56	900.89
999	2/6/2008	12:02	2306.672
999	2/6/2008	14:55	221.531
999	2/6/2008	23:05	1961.391
999	2/8/2008	20:32	959.859
999	2/11/2008	11:46	1216.028
999	2/12/2008	11:52	2396.032
999	2/12/2008	12:32	2233.026
999	2/12/2008	16:04	507
999	2/13/2008	9:58	993.234
999	2/16/2008	12:17	1226.746

Note: Data element tables were obtained from the ORCATECH Wiki Behavioral Assessment and Intervention Commons (BAIC) Database Guide. (ORCATECH, 2008)

Types of Data Collected:

1. Trigrams:
    a. Any time a user types while using Microsoft® Outlook or Microsoft® Word
    b. BRP.KCTrigrams Table: Column Names
        i. subjectID, EventDate, EventHour, KeyID0, KeyID1, KeyID2, Diff01, Diff12, AppId

Table 7: KCTrigrams

Key capture trigrams.

Column Name	Description
subjectId	Subject id
EventDate	Date of event
EventHour	Hour of event
KeyID0	Message id of first key
KeyID1	Message id of second key
KeyID2	Message id of third key
Diff01	Time difference between key0 and key1
Diff12	Time difference between key1 and key2
AppId	Application id

2. Passwords:

   a. User names and passwords that are typed in when a user tries to login via the computer monitoring software

   b. BRP.KCKeyData Table: Column Names

Table 8: KCKeyData

Keystroke information.

Column Name	Description
subjectID	Subject id
KeyID	Keystroke code (message id)
KeyCodes	Any modifiers reported for KeyID
EventDate	Date keystroke was recorded
EventTime	Time keystroke was recorded
MSec	Milliseconds from time

3. Application Focus Events:

   a. Any time a window gains focus (usually by mouse click)

   b. BRP.KCAppChange Table: Column Names

      i. subjectID, EventDate, EventTime, MSec, AppPath, AppTitle

Table 9: KCAppChange

Active window changes from user PC.

Column Name	Description
subjectID	Active subject id
EventDate	Date that event occurred
EventTime	Time that event occurred
MSec	Milliseconds from time
AppPath	Path of active window application
AppTitle	Title bar value of active window

4. Login Events

    a. Any time a user logs into their computer with our computer monitoring software installed

    b. KCLogins Table: Column Names

        i. subjectId, EventDate, EventTime, MSec, HomeId, Success

Table 10: KCLogin

BRPLogin events.

Column Name	Description
subjectId	Subject Id
EventDate	Date of login
EventTime	Time of login
MSec	Milliseconds from time
HomeId	Home id
Success	Whether login was successful or not (0/1)

5. Mouse Data: Click, double-click and mouse movements

    a. Updates no faster than every 15ms

    b. Updates no slower than every 5 pixels on screen

    c. Because of the sheer quantity of data that is collected each user has their own table in the database.

    d. KCMouseData.subject_(xx) Column Names:

        i. EventDate, EventTime, MSec, EventID, XPos, YPos

Table 11: KCMouseData

Active window changes from user PC.

Column Name	Description
EventDate	Date that event occurred
EventTime	Time that event occurred
MSec	Milliseconds from time
XPos	Horizontal position coordinate
YPos	Vertical position coordinate

The preceding tables offer an overview of the types of data elements studied relative to computerized monitoring of trigrams, passwords, application focus events, login events, and mouse data. They are detailed enough to provide a foundation for measuring some aspects of cognitive health. Examples include ability to focus and the aptitude for linguistic complexity as observed in formation of passwords and trigram keystrokes.

Socialization

Data was collected from subject personal computers that recorded interactions. Media included email, phone, and Skype™ audio/video/chat sessions. The goal was to report on the level of social engagement to determine if subjects had isolated themselves. HL7 CCD templates can be developed similar to the sleep management example.

Nicole Larimer, Cognitive Health Coaching Project Manager, provided key data needed to formulate the following synopsis. She gave a brief description of each element and its appropriate unit of measure, if applicable. For the purpose of clarifying data elements in this study, more detailed definitions were drafted.

Telephone Monitoring

Human social interaction can be conducted in various manners and by using a host of media. The ubiquitous telephone has long been a main staple for communication when distance or time separate people. Participant phone usage is a good indicator of the level of social engagement. The metrics measured from participant data are number of incoming and outgoing calls, call length, and call date.

Table 12: Sample Phone Raw Data

Sequence	HomeId	Mode	Code	Info	RecordTime	RecordDate	mSec
1	0	3	2	2480417	11:20:50	2008-03-20	593
2	0	2	4	001	11:21:30	2008-03-20	562
3	0	5	5	001	11:21:30	2008-03-20	750
4	0	5	0	001	11:21:31	2008-03-20	93
5	0	5	3	001	11:21:31	2008-03-20	718
6	0	5	4	001	11:21:33	2008-03-20	515
7	0	5	1	001	11:21:33	2008-03-20	906
8	0	5	8	001	11:21:34	2008-03-20	421
9	0	5	9	001	11:21:38	2008-03-20	187
10	0	5	3	001	11:21:38	2008-03-20	656

Table 13: Phone_CallerId

Caller id data reported from phone monitors.

Column Name	Description
Sequence*	Sequence id
HomeId*	Home id
Mode	(value returned from phone monitor)
PhoneNumber	Incoming phone #
PhoneId	(value returned from phone monitor)
Info	(value returned from phone monitor)
RecordDate	Date event occurred
RecordTime	Time event occurred
mSec	Milliseconds from time

Table 14: Phone_Events

Events recorded by phone monitors.

Column Name	Description
Sequence*	Sequence id
HomeId*	Home id
Mode	(value returned from phone monitor)
Code	Event code (value returned from phone monitor)
Info	(value returned from phone monitor)
RecordDate	Date event occurred
RecordTime	Time event occurred
mSec	Milliseconds from time

Modes

1 Caller ID, Number and Name
2 Line Status
3 Watchdog or Serial Number
4 Caller ID, Out of Area or Private
5 Touch Tone (DTMF)
8 Caller ID Signal Error

Line Status (Mode 2) Details

2 - 0 idle
- 1 ring start
- 3 off hook incoming
- 4 off hook outgoing

Note: Data element tables were obtained from the ORCATECH Wiki BAIC Database Guide. (ORCATECH, 2008)

Call duration and the time of day can be used to gauge willingness to socialize. Cognitive health coaches may also establish activity patterns and determine if they are positive or detrimental. Analyzing Caller ID data can inform observers about call origination. This information is important because it allows for better understanding about why a particular call may have been dropped quickly or was extended. The former might imply telemarketing contacts, while the latter involves a conversation with a loved one.

Skype™ Usage

Skype™ and other voice-over-IP (VoIP) solutions have quickly become just as popular as the telephone as a mode of communication. The advantage of the newer technology is reliable, low-latency interaction using tools like chat and videoconferencing. Skype™ metrics include call length and the number of chat messages made by participants. This information is exported to an XML format from the participant's computer. The XML document is then uploaded to a server where it is processed and entered into a database. The raw database schema is yet to be designed, but will likely follow the same format as the XML file. (*Format possibly subject to change, but the general intent should be clear.)

Raw XML data format:


```
<chat_history id="hattwj" name="hattwj">
        <message>
          <body type="chat"/>
          <date>1260214396.0</date>
          <origin id="jimisonh">Holly B Jimison</origin>
          <destination id="hattwj">hattwj</destination>
        </message>
        <message>
          <body type="audio-video">
                <partlist alt="">
                  <part identity="jimisonh">
                    <name>Holly B Jimison</name>
                    <duration>135</duration>
                  </part>
```

```
            <part identity="hattwj">
              <name>hattwj</name>
              <duration>135</duration>
            </part>
          </partlist>
    </body>
    <date>1260214532.0</date>
    <origin id="jimisonh">Holly B Jimison</origin>
    <destination id="hattwj">hattwj</destination>
  </message>
</chat_history>
```


As will be discussed in the results section, a health coach or clinician might find Skype™ total number of calls, call length, the number of chat messages, and other metrics valuable to the overall patient assessment. The XML data is parsed and ported to the database server for storage. Then an informatician manipulates the data for meaningful reporting in PHRs and EHRs.

Research PHR Systems to Develop Standardized Summaries

PHR systems are like many other product categories in that they are replete with differences and similarities. Microsoft® HealthVault™ and Google® Health are compared in this section to provide readers with an understanding of their respective features and limitations. Measurements and data representation are discussed for each PHR and then recommendations for summary report design is presented.

Microsoft® HealthVault™

Microsoft® HealthVault™ enables users to store, organize, and share health information from many sources in one online location. (What HealthVault can do for you, 2010) The solution interoperates with doctors, hospitals, employers, pharmacies, insurance providers, and manufacturers of health devices to facilitate adding health record information electronically to the Microsoft® HealthVault™ record. All of these stakeholders ultimately work together toward one common end, making informed decisions.

Compatible Devices

A growing number of weight scales, blood glucose monitors, blood pressure monitors, pedometers, pulse oximeters, heart rate monitors, and other devices gather valuable information and store it in one central location. (Devices that connect with HealthVault, 2010) Connection technologies include embedded Bluetooth®, cellular, and Wi-Fi®. Those with the “Works with HealthVault” logo meet Microsoft’s highest standard for HealthVault connectivity.

Health and Fitness Partner Sites

Health and fitness partner use data in the Microsoft® HealthVault™ record to help improve users' health. They start by showing the types of data they want to access and request permission to do so. Once data is added to a user's record, it can be used at other sites that employ that data type. The following list contains several examples of the many partner sites (Health and fitness sites that connect with HealthVault, 2010):

Table 15: Microsoft® HealthVault™ Partner Sites

Partner	Description
20/20 LifeStyles	The 20/20 LifeStyles program offers a multidisciplinary approach to the treatment of obesity and related metabolic imbalances including diabetes, high cholesterol, high blood pressure and depression.
Aetna Personal Health Record	Aetna's Personal Health Record includes member health information based on claims and user-entered data, and delivers online health alerts and reminders.
PatientSite (Beth Israel Deaconess Medical Center - BIDMC)	BIDMC is a patient care, teaching and research affiliate of Harvard Medical School. BIDMC offers a patient portal, called PatientSite, which connects its patients to their medical records online.

Microsoft® HealthVault™ Developer Center

The Microsoft® HealthVault™ Developer Center contains the Software Development Kit (SDK) and supporting content that guides software developers in the creation of Web applications that are compatible with Microsoft® HealthVault™. (Getting Started with the Microsoft HealthVault SDK, 2010) The previously described partner sites are examples of such Web applications. A common goal might be connecting a clinical system to "…facilitate the voluntary exchange of information between patients and healthcare providers." (Connecting a Clinical System to HealthVault, 2010). Lamprey Networks and IBM (refer to Appendices) provide expert consulting and development services in the PHR and EHR realms.

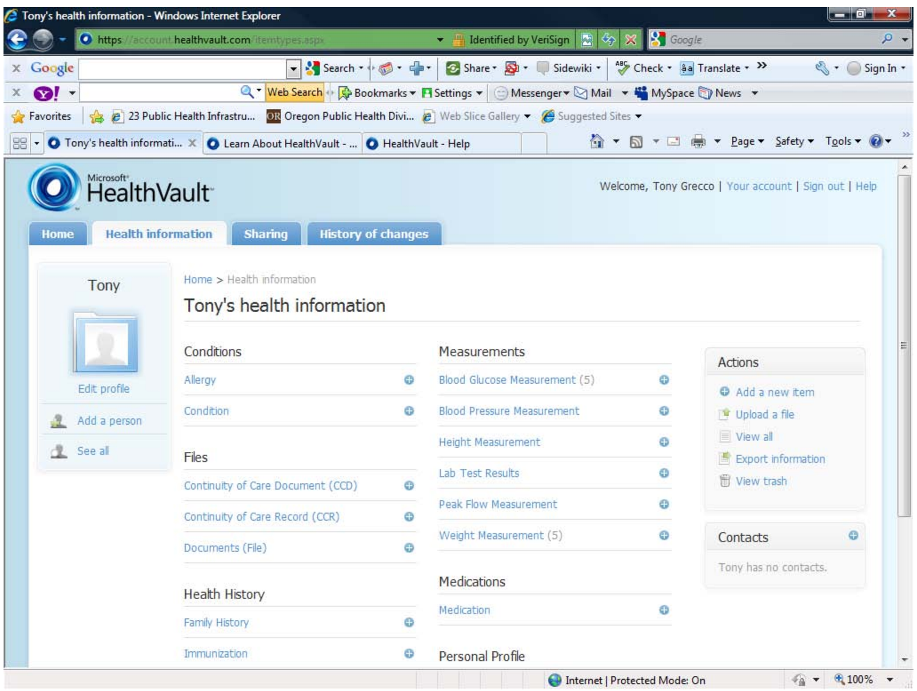
Microsoft® HealthVault™ Connection Center

Microsoft® HealthVault™ Connection Center is free software that helps the user track progress and manage health and fitness goals. (About Microsoft Healthvault Connection Center, 2010) The tool runs on a user's computer and acts as a bridge between his health and fitness devices and personal account at the Microsoft® HealthVault™ Web site. Capabilities include charting progress, printing out information for health advisers, and using HealthVault-connected Web sites to achieve health and fitness goals.

General Graphical User Interface (GUI)

The Microsoft® HealthVault™ Health Information tab presents an overview of the user's health information. An account was created to demonstrate basic feature elements. The health information herein was fictitiously contrived for reader edification.

Figure 4: Health Information



Measurements

Various types of medical measurements can be entered into the application manually, via approved devices, or through shared partner sites. Default reports are elementary but may be customized using the Microsoft® HealthVault™ Developer Center SDK. The subsequent two examples provide a glimpse of the initial layout. These concepts are carried forward into this researcher's ideas for summary reports relevant to the cognitive health coaching project.

Figure 5: Health Information – Blood Glucose Measurement

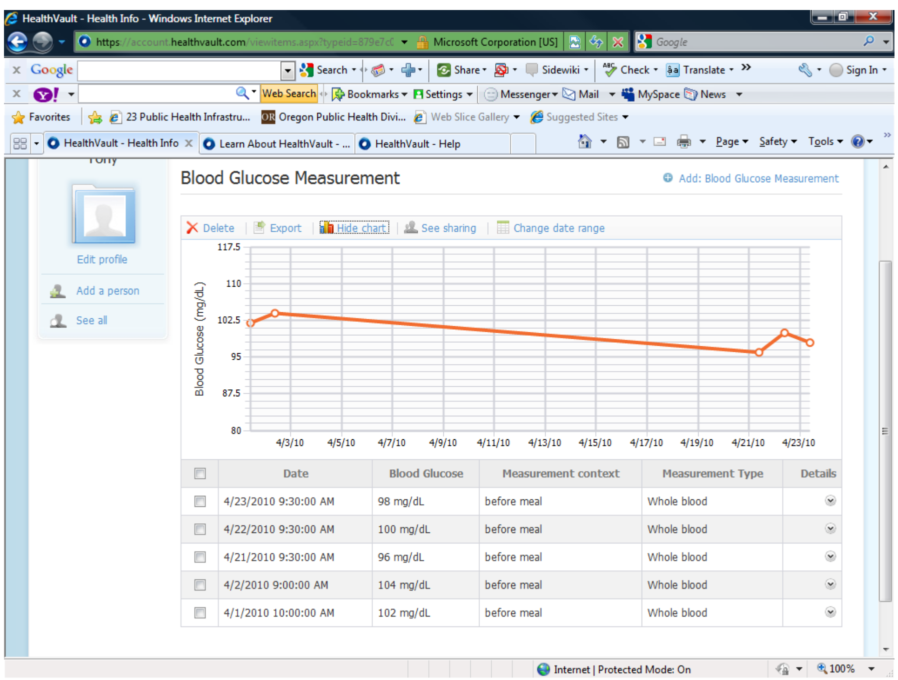
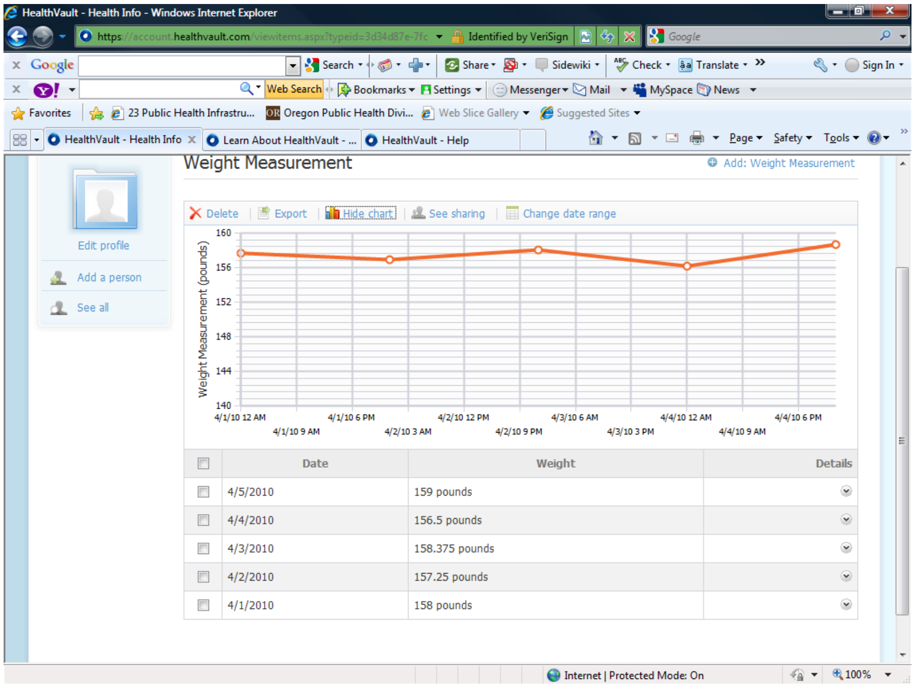


Figure 6: Health Information – Weight Measurement



Google™ Health

Google™ Health enables users to store, manage, and access health information from many sources in one online location. (About Google Health, 2010) The solution also interoperates with doctors, hospitals, employers, pharmacies, insurance providers, and manufacturers of health devices to facilitate adding health record information electronically to the Google™ Health record. Users can build online health profiles, import medical records from hospitals and pharmacies, share health records, and explore online health services.

Compatible Devices

Similar to Microsoft® HealthVault™, a growing number of weight scales, blood glucose monitors, blood pressure monitors, pedometers, pulse oximeters, heart rate monitors, and other devices gather valuable information and store it in one central location. Connection technologies include embedded Bluetooth®, cellular, and Wi-Fi®. A February 2009 IBM press release described its teaming with Google™ Health and the Continua® Health Alliance:

> "**ARMONK, NY - 04 Feb 2009:** IBM (NYSE: IBM), in collaboration with Google and the Continua Health Alliance, today announced new software that will enable personal medical devices used for patient monitoring, screening and routine evaluation to automatically stream data results into a patient's Google Health Account or other personal health record (PHR). This breakthrough extends the value of PHRs to consumers and also helps to ensure that such records are current and accurate at all times. Once stored in a PHR, the data can also be

shared with physicians and other members of the extended care network at a user's discretion.” (IBM Teams With Google and Continua Health Alliance to Move Data From Remote Personal Medical Devices Into Google Health and Other PHRs, 2010)

Health and Fitness Partner Sites

These health and fitness partner sites use data in the Google™ Health record to help improve users’ health. They start by showing the types of data they want to access and request permission to do so. Once data is added to a user’s record, it can be used at other sites that employ that data type. The following list contains several examples of the many partner sites (Partner Profiles, 2010):

Table 16: Google™ Health Partner Sites

Partner	Description
Anvita Health	Anvita Health provides software that instantly personalizes, prioritizes, and identifies treatment options to help patients and doctors make better decisions and avoid medical errors.
Blue Cross Blue Shield of Massachusetts	Today, up to two years of a member's Blue Cross Blue Shield of Massachusetts health history including conditions, procedures, and medications, can be imported into Google Health to give them online access to their health care and claims records.
The Cleveland Clinic	Working with Google Health, Cleveland patients can now import their Cleveland Clinic medical records into their own, secure Google Health Account.

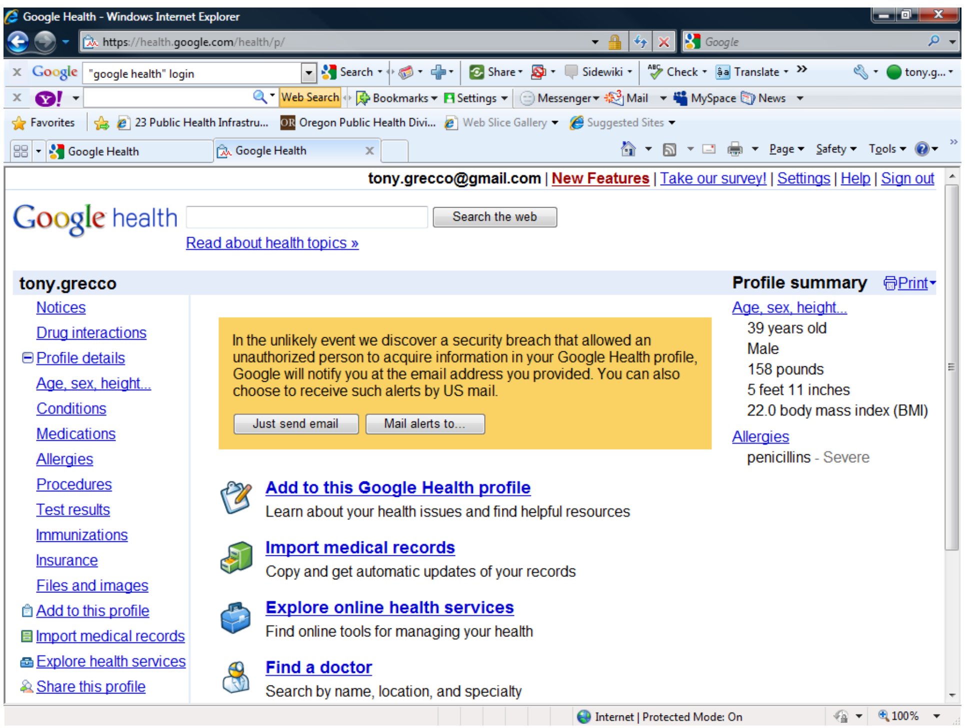
Google™ Health APIs and Integration

"The Google™ Health APIs enable institutions to send and access health information from users' Google™ Health profiles after permission has been granted." (Google Health Integration Policies, 2010) Partners can choose to develop their applications using these APIs or they can opt to contract with integration consultants listed on the Google™ Health Web site: Mount Tabor Online Services, Medicom Digital, and Iatric Systems. (Google Health Integration Consultants, 2010) Lamprey Networks and IBM (refer to Appendices) also provide expert consulting and development services in the PHR and EHR realms.

General Graphical User Interface (GUI)

The Google™ Health home screen presents an overview of the user's health information. An account was created to demonstrate basic feature elements. The health information herein was fictitiously contrived for reader edification.

Figure 7: Home Screen



Measurements

Various types of medical measurements can be entered into the application manually, via approved devices, or through shared partner sites. Default reports, accessed through the "Test results" link, are elementary but may be customized. The subsequent two examples provide a glimpse of the initial layout. These concepts are carried forward into this researcher's ideas for summary reports relevant to the cognitive health coaching project.

Figure 8: Test Results – Blood Glucose (Graph View)

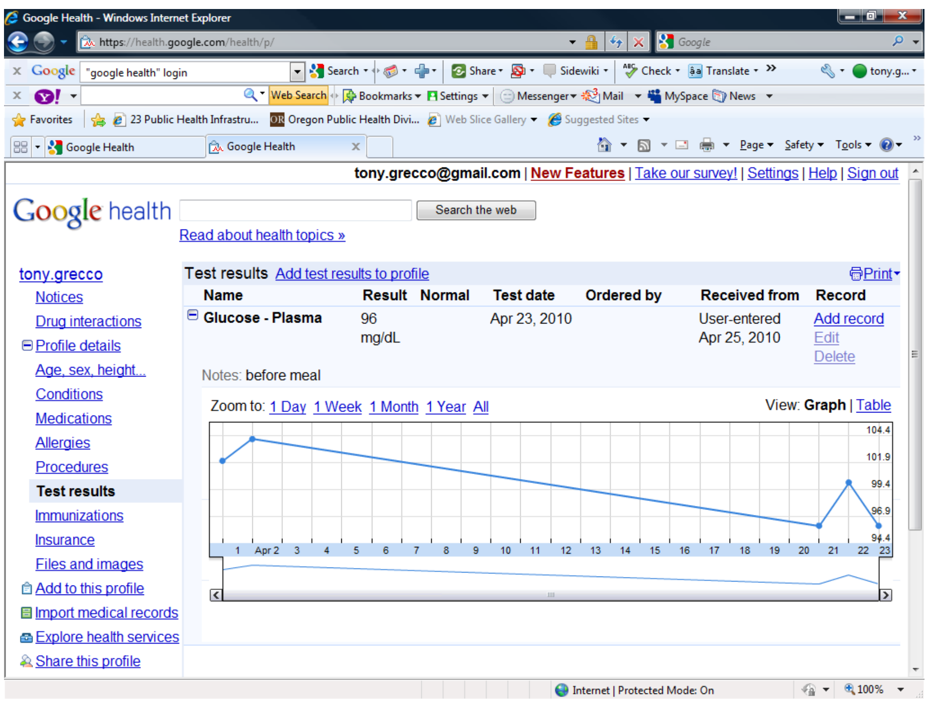


Figure 9: Test Results – Blood Glucose (Table View)

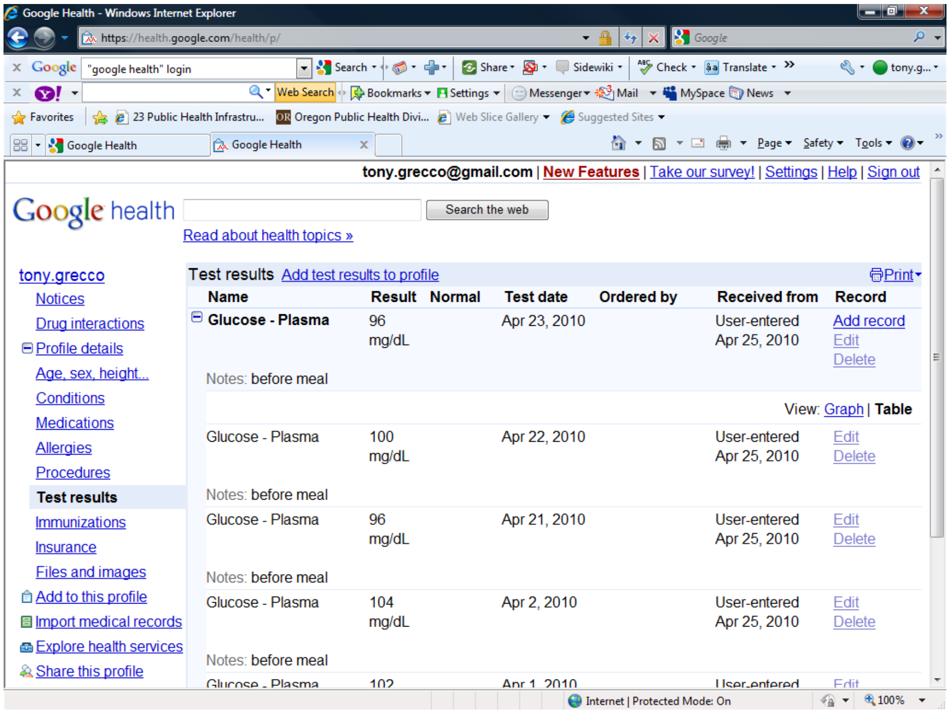


Figure 10: Test Results – Body Weight (Graph View)

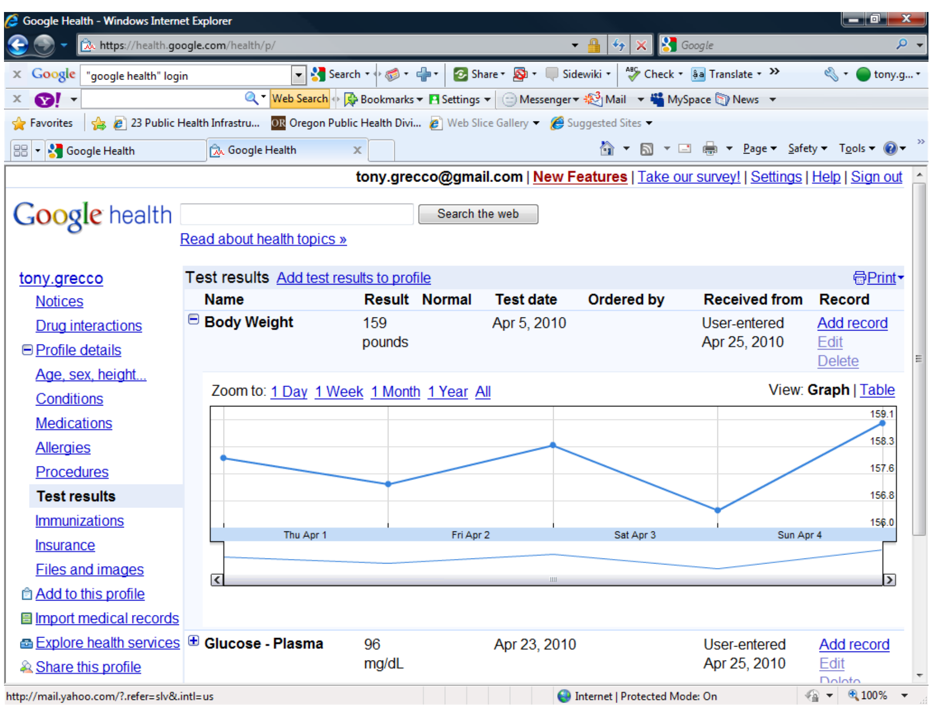
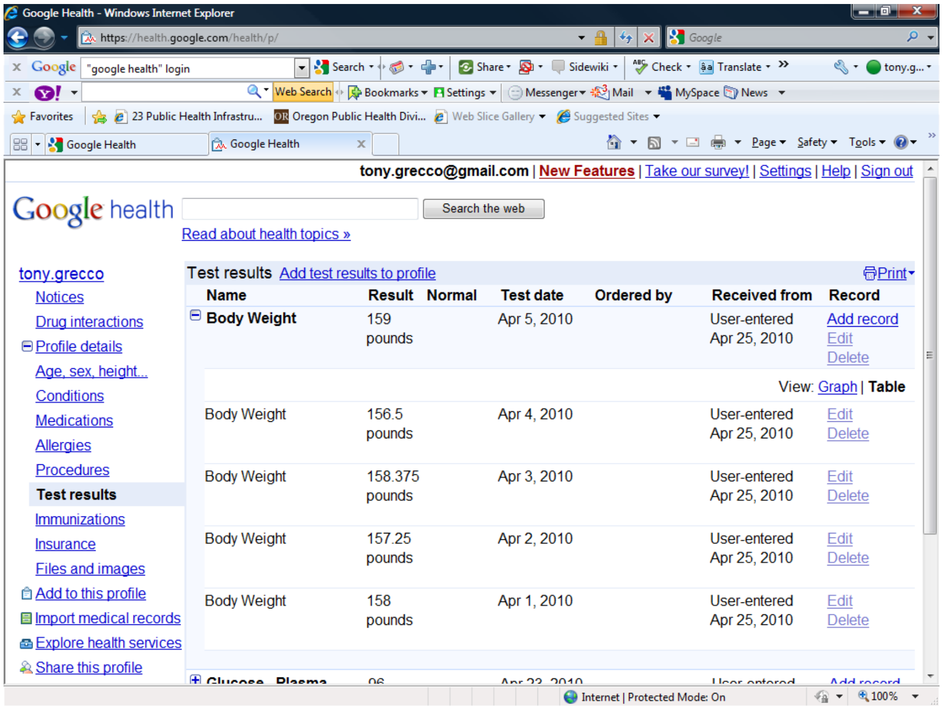


Figure 11: Test Results – Body Weight (Table View)



The preceding descriptions and graphics showed differences and similarities between Microsoft® HealthVault™ and Google® Health PHRs. Both tools displayed measurement test results in similar table and graph formats. Each also offered comparable data input methods. Partner sites were plentiful for the two competitors and relative ease of customization was conveyed by mentioning a Microsoft SDK and Google APIs. However, notable differences could be seen in site navigation, aesthetics, and terminology.

Proposed Cognitive Health Coaching PHR Summary Reports

Copious data analyses were conducted in a separate spreadsheet document in an effort to create summary reports for the new cognitive health coaching variables described in this paper. Based on results from the PHR research results, templates are offered for select tests in sleep quality, cognitive performance, and socialization. These models will aid the team in developing customized PHR summary reports in the next project iteration.

Sleep Quality

The BAM Sleep Center dashboard (BAM Sleep Center, 2010) shown in Table xx provided a comprehensive, yet concise, representation of patient data. Chart xx focuses on time in and out of bed. Other factors can be represented in a similar summary format.

Figure 12: BAM Sleep Center Dashboard

Summary

	Last Session	Your 30 Day Average	Delta to Average	Goal
Time went to bed	08:37PM	08:47PM	-10 Min 0 Sec	
Time got out of bed	06:00AM	06:10AM	-10 Min 0 Sec	
Total Time in Bed	9 Hrs 22 Min	8 Hrs 3 Min	1 Hrs 19 Min	
% of Motion During Sleep	13%	13%	0%	
Restful Time	8 Hrs 9 Min	7 Hrs 0 Min	16%	
Time Asleep	7 Hrs 23 Min	5 Hrs 27 Min	35%	8 Hrs 0 Min
In & Out of Bed	1	1	0%	0
Sleep Balance	-36 Min 36 Sec	-2 Hrs 32 Min	-75%	0
Average Heart Rate	64	47	36%	60 - 80
Average Breathing Rate	17	16	6%	15 - 25

Figure 13: Sleep Quality Summary

Cognitive Performance

Cognitive performance measurements and data representation for EHRs were comprised of games and computer monitoring:

Games

Existing Simple Metrics

Length of time spent playing each game, number of games played, and the final score of each game were initially identified by the team as simple metrics.

Cognitive Domain Measures

- Verbal fluency
- Short-term and working memory
- Divided attention
- Motor speed
- Planning and other aspects of executive function

Additional Metrics

This study proposed some additional ways of presenting longitudinal results to health coaches and caregivers. The health coach determines the session length. The data set measured in this scenario spans nearly two years. A more realistic range would be daily, weekly, or monthly.

Each column from "Avg. Games/Day" forward would depend on the established session lengths. "Avg. Games/Week" and "Avg. Games/Month" values were calculated by multiplying "Avg. Games/Day" by seven and thirty, respectively. The "Weekly Avg. Score" and "Monthly Avg. Score" values were calculated similarly using the first seven and thirty scores, respectively.

Despite the unusually long session used in this example, the principle to impart is the sizeable sample population (676 games) creates an argument for statistical validity. A condensed version of the table may be used to match coaching requirements. Aesthetics and human-computer interaction heuristics would also dictate the interface design.

Table 17: Games Raw Data Elements

Game	Start Date	End Date	# Days in Range	Total # of Games	Overall Avg. Score	Overall Avg. Time/Game	Overall High Score	Overall Low Score	Overall Median Score	Avg. Games/Day	Daily Avg. Score	Avg. Games/Week	Weekly Avg. Score	Avg. Games/Month	Monthly Avg. Score
Pyramid Builder	2/29/2008	2/17/2010	719	676	2804	2:38	10710	10	2360	0.94	2234	6.58	2420	28.21	2118
Spelling Bee															
Letter Lotto															
21 Tally															
On the Flipside															
Solitaire															
Sudoku															
FreeCell															
Scavenger Hunt															

The data shown in Table 17 can then be consolidated and summarized in graphical form as shown in Figure 16. A health coach would focus on game usage to track the strength and adherence to the intervention and on the cognitive metrics derived from the user's computer interactions during game use. For example, an estimate of a user's working memory "buffer length" is derived from performance on the Flipside memory game. An estimate of verbal fluency is derived from performance measures from the Letter Lotto and Spelling Bee word games. Similarly, a planning measure is obtained from FreeCell use and a divided attention measure from the two-dimensional Black Jack game of 21 Tally.

One can see the potential for a games dashboard and additional statistical output that may be deemed constructive for cognitive health coaches. The continuous nature of the data over time provides the coach with trend information for each of these cognitive metrics, as well as a measure of variability. In response, the coach can then intervene and recommend particular activities to address declining or low-value measures. These data output designs could be migrated to PHRs through customization tools such as SDKs and APIs.

Computer Monitoring

Computerized monitoring of trigrams, passwords, application focus events, login events, and mouse data assist cognitive health coaches assess the ongoing status of participants' health. Two general metrics of interest for PHR summary reporting are the number of computer usage sessions and average time spent in each session.

Figure 14: Computer Usage - Monthly Session Count

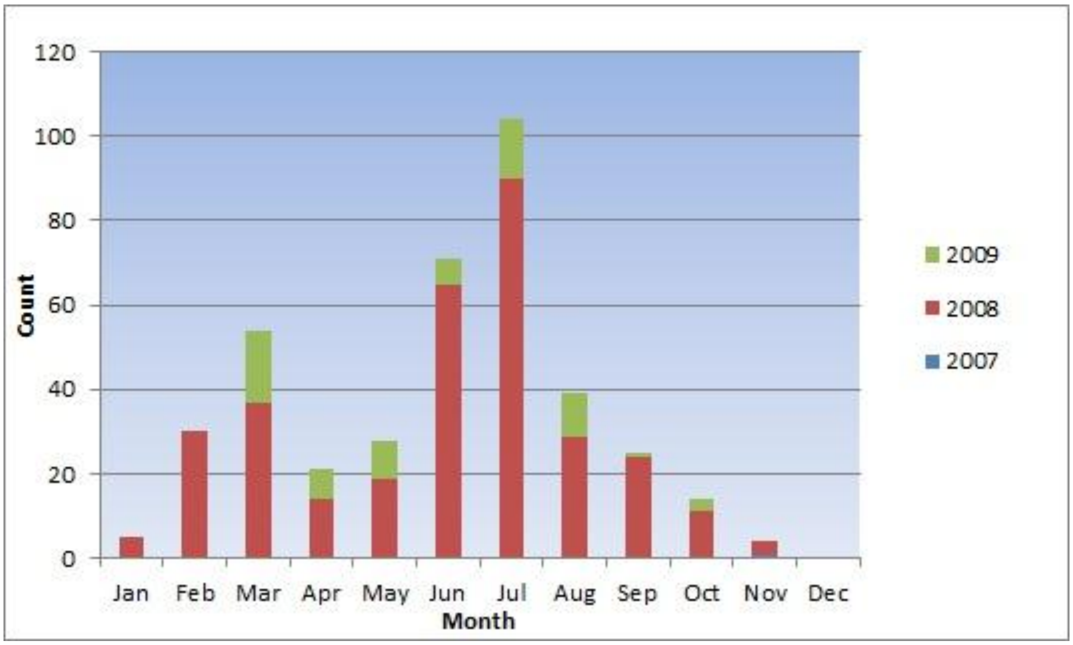
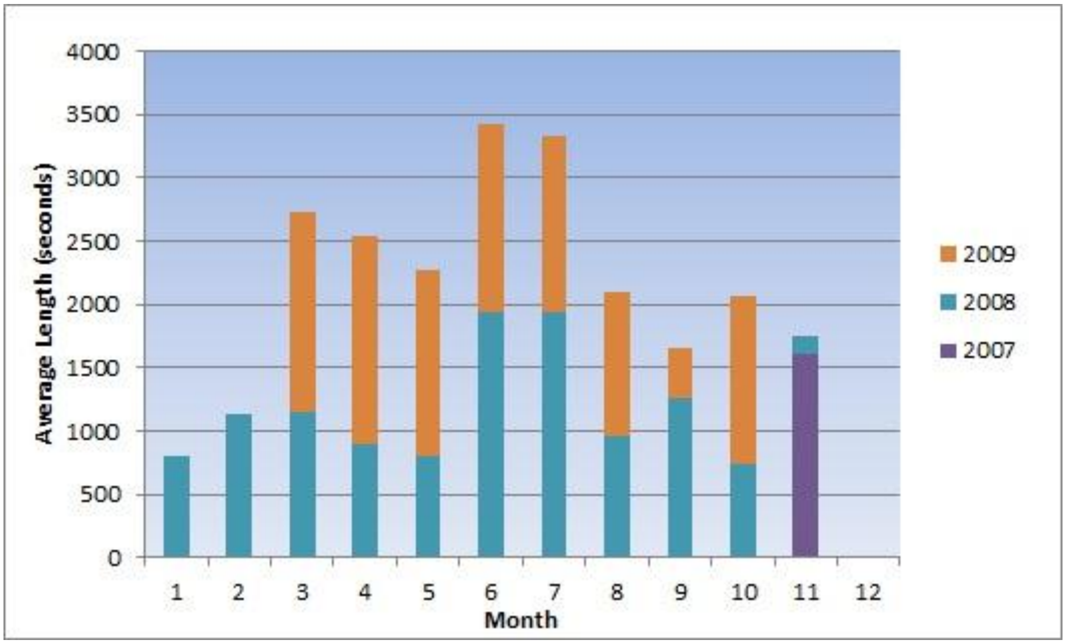


Figure 15: Computer Usage - Monthly Average Session Length

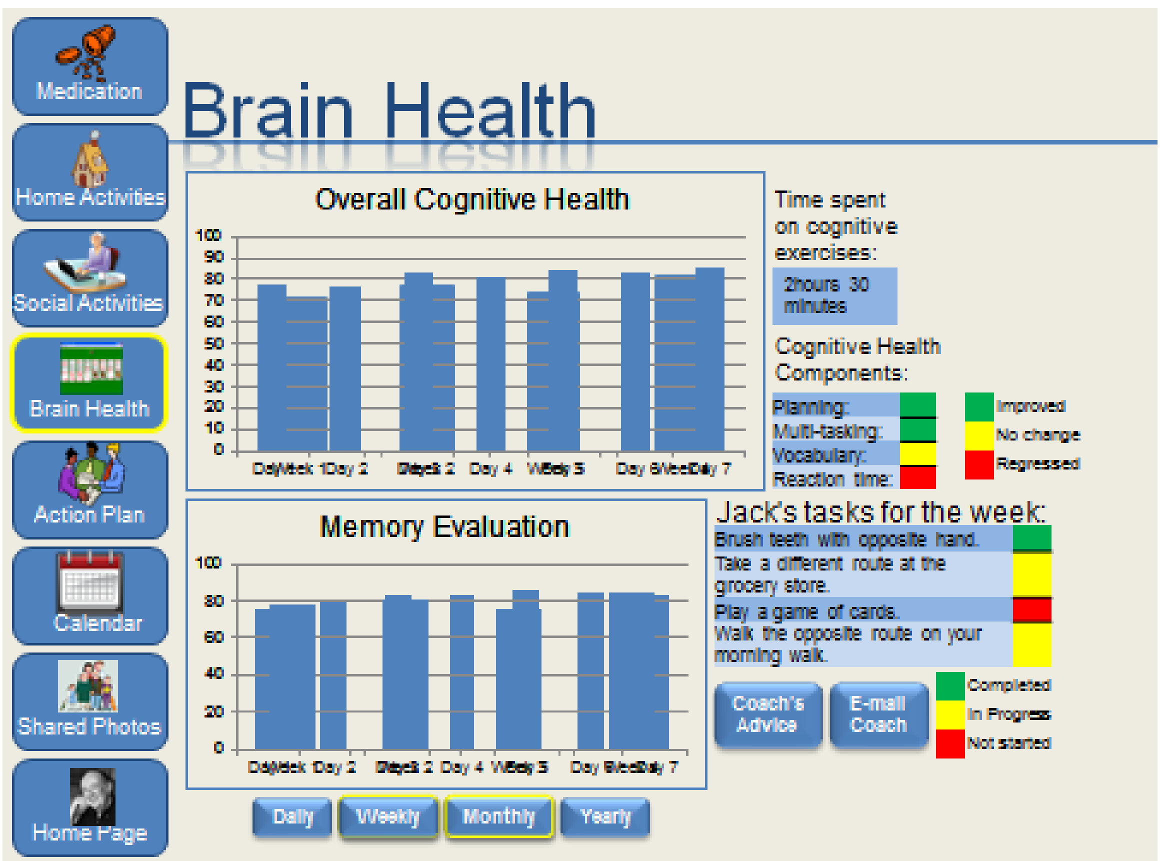


Data in the foregoing charts appears erratic but the lack of a pattern does not eliminate the possibility for interpretation. One can determine the rather obvious assumption that data collection did not begin until October or November 2007. 2008 was marked with peak session volume and duration during the summer. Finally, the two variables were steady in 2009 and then waned in latter months. A health coach, adequately informed about a patient's regular daily activity and cognitive condition, could ascertain what these patterns indicate.

Cognitive Performance Data Representation Summary

The preceding cognitive performance graphics contained games and computer usage details that proved useful in creating the following high-level summary. Figure 16 consolidates these data into a view that can be more easily comprehended in a glance for the benefit of health coaches and caregivers. In this case, overall cognitive health is displayed for the week, as well as memory. An even higher level summary of additional cognitive measures, such as planning, divided attention, verbal ability and reaction time, is shown to the right. Other cognitive data types can be added as they are included in future project iterations.

Figure 16: Cognitive Performance Coach & Family Display

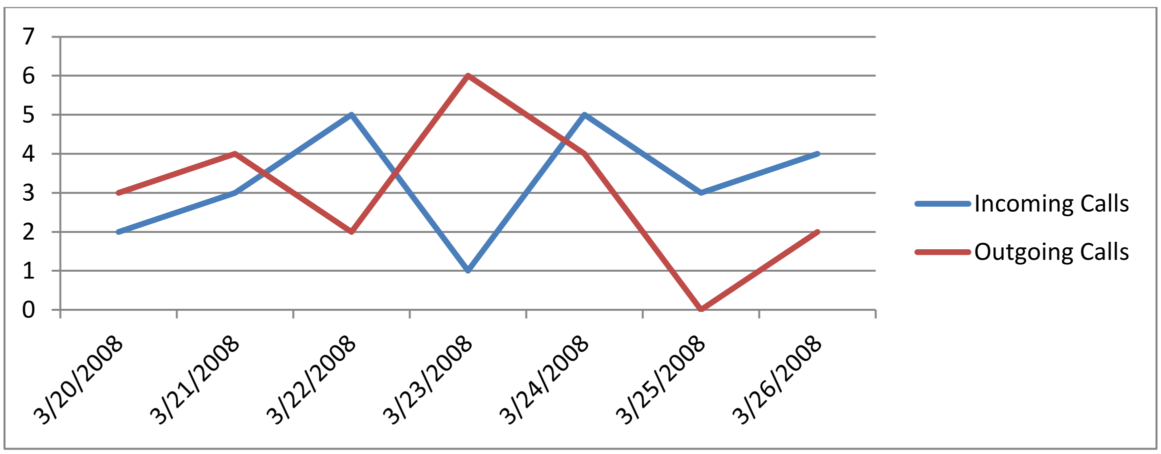


Socialization

Telephone Monitoring

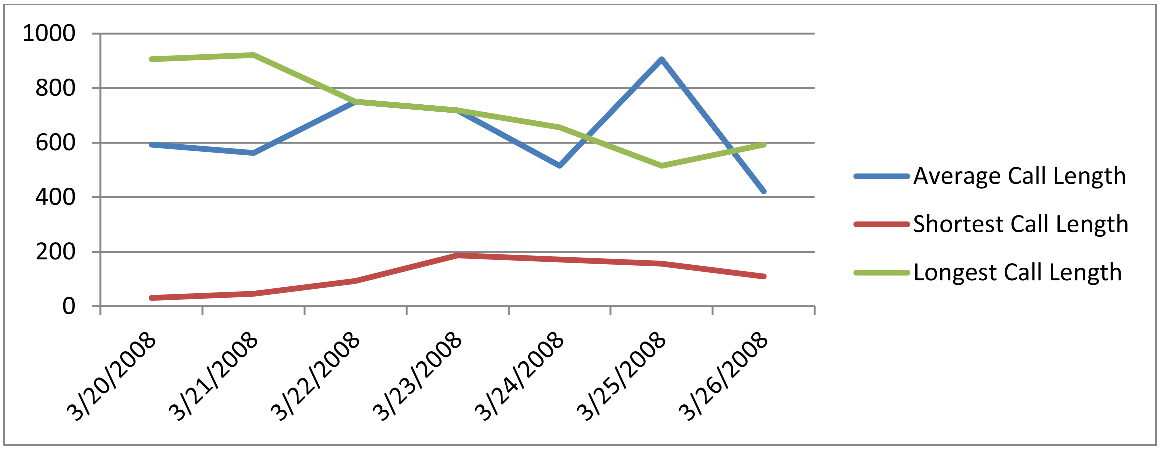
The definitions section talked about the ubiquitous telephone being a main staple for communication when distance or time separate people. Participant phone usage is a good gauge of social engagement. The metrics measured from participant data were number of incoming and outgoing calls, call length, and call date. All three data elements were incorporated in the following two data representations.

Figure 17: Daily Telephone Call Volumes



	Thu 3/20/2008	Fri 3/21/2008	Sat 3/22/2008	Sun 3/23/2008	Mon 3/24/2008	Tue 3/25/2008	Wed 3/26/2008
Incoming Calls	2	3	5	1	5	3	4
Outgoing Calls	3	4	2	6	4	0	2
Total Calls	**5**	**7**	**7**	**7**	**9**	**3**	**6**
Avg. Call Length (secs)	593	562	750	718	515	906	421
Shortest Call Length (secs)	31	46	93	187	171	156	109
Longest Call Length (secs)	906	921	750	718	656	515	593

Figure 18: Daily Call Lengths (seconds)



	Thu 3/20/2008	Fri 3/21/2008	Sat 3/22/2008	Sun 3/23/2008	Mon 3/24/2008	Tue 3/25/2008	Wed 3/26/2008
Incoming Calls	2	3	5	1	5	3	4
Outgoing Calls	3	4	2	6	4	0	2
Total Calls	**5**	**7**	**7**	**7**	**9**	**3**	**6**
Avg. Call Length (secs)	593	562	750	718	515	906	421
Shortest Call Length (secs)	31	46	93	187	171	156	109
Longest Call Length (secs)	906	921	750	718	656	515	593

These weekly snapshots reveal a couple of insightful messages. Daily incoming and outgoing call volumes have an inverse relationship during the majority of the week. Also, average call lengths are steady throughout the week until a peak toward the end. The longest call lengths line decreases as the week progresses. Translation of the data requires knowledge about the patient and his individual case specifics.

Skype™ Usage

Skype™ metrics included call length and the number of chat messages that were made by participants. The raw database schema is yet to be designed, but will likely follow the same format as the original XML file. The proposed summary report for the current study involved a logical assessment of results. However, calculations were not performed because the data output was not conducive to spreadsheet or statistical software analyses.

Table 18: Skype™ Usage Dashboard

Date Range: 1/1/10-1/31/10	Daily	Weekly	Monthly	Date (Daily)
Overall Calls Summary				
Total Calls				
Avg. # Calls				
Avg. Call Length				
Shortest Call Length				
Longest Call Length				
Audio Call Summary				
Total Audio Calls				
Avg. Audio Calls				
Shortest Call Length				
Longest Call Length				
Audio-Video Call Summary				
Total Audio-Video Calls				
Avg. Audio-Video Calls				
Shortest Call Length				
Longest Call Length				
Chat Sessions Summary				
Total # Chat Sessions				
Avg. # Chat Sessions				
Lowest # Chat Sessions				
Highest # Chat Sessions				
Chat Messages Summary				
Total # Chat Msgs.				
Avg. # Chat Msgs.				
Lowest # Chat Msgs.				
Highest # Chat Msgs.				

NOTE: The "Date Range" determines which cells are visible and populated. For example, a one-month range should present monthly totals, averages, shortest/lowest, and longest/highest values.

Interpretation of a populated chart would entail analysis similar to the telephone monitoring scenario. Incoming and outgoing call volumes and call lengths are important factors to form conclusions. The case of Skype™ usage is unique in that it provides even more granularity and dissection of social interaction. A health coach can additionally evaluate the significance of audio-only calls, audio-video calls, chat sessions and combinations of each communication mode. A patient may innately prefer a particular method or decreased use of one type could be a sign of withdrawal.

Socialization Data Representation Summary

The preceding socialization graphics contained a great deal of detail that proved useful in creating the following high-level summaries. Figures 19 and 20 consolidate these data into two views that can be more easily comprehended in a glance for the benefit of health coaches and caregivers. Email and other socialization channel data can be added as they are included in future project iterations.

Figure 19: Social Activities - Phone and Skype™ Usage Volume Dashboard

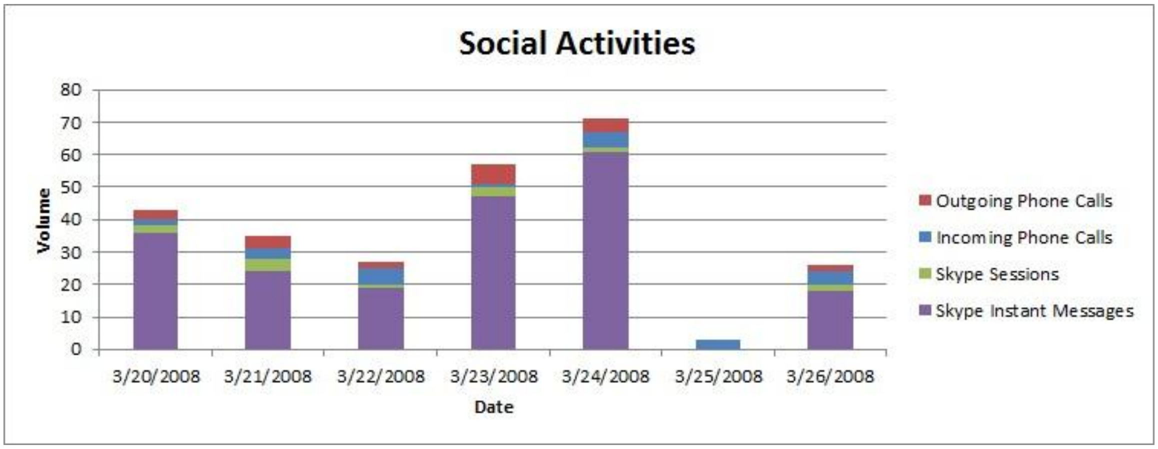
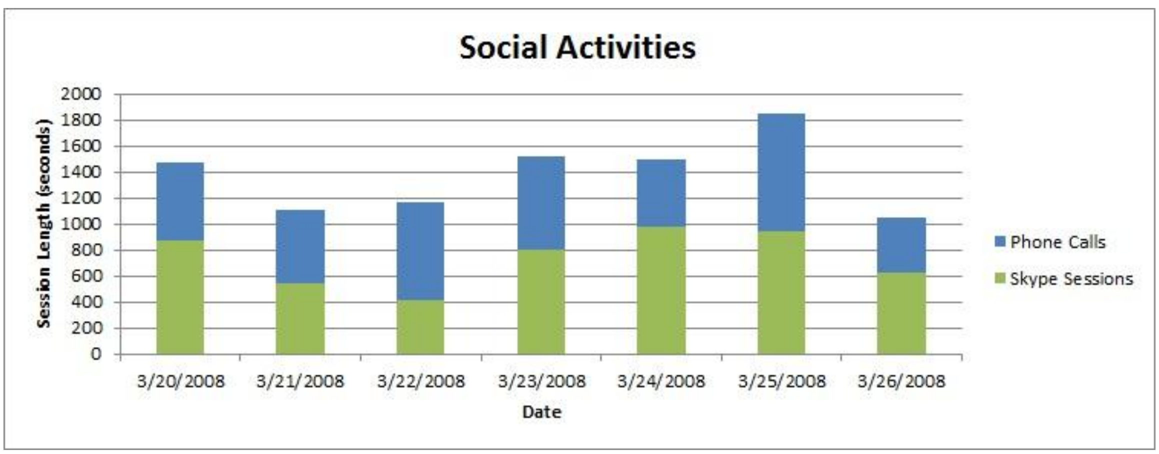


Figure 20: Social Activities - Phone and Skype™ Usage Session Length Dashboard



Summary of PHR Research Section

Based on results from the PHR research results, templates were presented for select tests in each of the three main study categories: sleep management, cognitive monitoring and remediation, and socialization. Value can be obtained if the cognitive health coach and patient have a good working relationship. To reiterate, these models will aid the team in developing customized PHR summary reports in the next project iteration.

Consult with OHSU Staff to Develop EHR Summary Reports

Proposed summary reports created for PHR vendors, and their subsequent recommendations, were carried forward to this section for presentation to OHSU staff members and grant researchers. Their varying skill sets and knowledge were deemed crucial in order to obtain comprehensive advice regarding data representation in cognitive health coaching summary reports within an EHR. A ninety-minute information gathering ("brainstorming") session was conducted with these personnel on May 5, 2010. A summary of the interactions is presented in the proceeding section. Additional feedback was subsequently gleaned from some individuals via emails and individual interviews.

Initial Meeting Attendees:

- Susan Butterworth has a background in health coaching. She has more recently focused on incorporating behavioral change science into disease management and health coaching, motivational interviewing, and patient activation (self-care).
- Bill Herzberg, MD, practiced as a clinical neurologist for many years. He has more recently transitioned to a research role exploring neurophysiology and muscular and sleep disorders.
- Jeff Jensen graduated from OHSU's Department of Medical Informatics and Clinical Epidemiology (DMICE) master's program in 2009. He is currently an OHSU Information and Technology Group (ITG) Systems Applications Analyst for the Epic® MyChart EHR. Some of Jeff's duties include training, implementation and technical support.

- Misha Pavel, PhD, is Chair of the OHSU Biomedical Engineering Department.
- Holly Jimison, PhD, is an OHSU DMICE Associate Professor. She is the principal investigator for the Cognitive Health Coaching Program. Dr. Jimison is also my advisor for this Capstone project.

Information Gathering Session Summary

Attendees were asked to comment on the topics listed below, with Epic topics reserved for a later discussion with Jeff Jensen via teleconference and collaboration software. The session began with an orderly flow but then morphed into an open forum. The resulting approach proved more conducive to obtaining practical and realistic responses. Everyone shared ideas and comments spawned tangential conversations. (Butterworth, Herzberg MD, Jensen, Pavel PhD, & Jimison PhD, 2010)

Summary Reports and Data Representation

- Charts, graphs, tables, etc.
  - Susan Butterworth: An overview with a dashboard is helpful. Thresholds for risk factors should alert report viewers by using emboldened and color-coded (e.g., red) text.
  - Dr. Bill Herzberg: Summarize data but give report viewers the ability to drill down on specific factors. Some additional sleep measurements to consider for future research are Circadian rhythm, rituals and habits, and ambient light (unit = lux) as it relates to sleep hygiene

    - Misha Pavel, PhD: Future studies should incorporate balance metrics and gait velocity analysis. The Nintendo® Wii™ gaming system might be an ideal tool.
    - Holly Jimison, PhD: Some medical students suggested light therapy, such as a lamp near a computer, could be an important variable.
- Time periods: Everyone agreed longitudinal data over any given time period provides a useful trending review.
- Averages, lowest/highest values, highlight lower/upper thresholds
    - Susan Butterworth: A visual scale, with trending, of 1-100 can assist in the assessment of sleep quality. Example: "How do you feel today?" or "How would you rate the restfulness of your sleep?"
    - Dr. Bill Herzberg: One or two significant variables should be sufficient. Subjective and objective measurements can be equally important.
    - Holly Jimison, PhD: Study participants each receive a weekly questionnaire on their computers.
- What do clinicians want to see?
    - Susan Butterworth: Most health coaches are not technically inclined because their role involves social skills. Clinicians are often more technical and may want to have drill-down capabilities.
    - Holly Jimison, PhD: Clinicians may want to see sleep measurements concerning anxiety, interruptions, and time of day.

Follow-up Feedback from Dr. Bill Herzberg

Bill Herzberg, MD, practiced as a clinical neurologist for many years. He has more recently transitioned to a research role exploring neurophysiology and muscular and sleep disorders.

Dr. Herzberg offered insightful thoughts on "unobtrusive monitoring of the elderly at home" (Herzberg MD, 2010). The following message summarizes some very useful summary reporting recommendations, which were considered when devising proposed EHR reports. This excerpt stems from the complete email message found in the Appendix.

> "We can get a good sense of 1) duration of sleep in bed corresponding to motionless time in bed 2) time onset of sleep 3) time offset of sleep 4) sleep efficiency 5) frequency of arousals from sleep and 6) perhaps apneas. Without EEG, muscle tone, eye movement data we can't definitely score REM versus NREM sleep, but we can predict REM based on irregular heart rate, irregular respiratory cycle and SWS (slow wave sleep or deep NREM) based on regular heart rate and respiratory rate and arousals based on motion plus irregular HR and RR.
>
> There is a lot of variability in sleep parameters in the elderly, so it may be more useful to compare subjects to their own baseline rather than normative data.
> I think it's easy to drown in too much information or information which is ill displayed. I would display information over time graphically ideally

summarizing sleep, mobility, cognitive function, socialization, metabolism by single numbers. I would generate a sleep number based on deviation from baseline sleep efficiency, arousals, total sleep time, sleep phase and perhaps subjective sleep quality and daytime sleepiness. If this number changes I would allow the viewer to expand the number into its various components interactively rather than always displaying all the data."

Follow-up Feedback from Jeff Jensen

Jeff Jensen graduated from OHSU's Department of Medical Informatics and Clinical Epidemiology (DMICE) master's program in 2009. He is currently an OHSU Information and Technology Group (ITG) Systems Applications Analyst for the Epic® MyChart EHR. Some of Jeff's duties include training, implementation and technical support.

Jeff Jensen sent an email on 5/7/10 providing useful responses to the summary reports and Epic-specific questions used in the initial group interview (Jensen, 2010):

Regarding Summary Reports and Data Representation:

- Charts, Graphs, etc.: Summary is key for most users, with the capability to display information in different formats

- Time Periods: Use custom ranges and predefined periods, such as "last X minutes/hours/days/months."

- Averages, Values, Thresholds: Depending upon the information, users may want to see additional information. Examples include averages/trends, or adjusted norms applied, reference ranges, etc.

- What clinicians want to see: Ultimately I think this would depend upon the situation and the type of clinician.

Pertinent to Epic:

- Does Epic summarize data?: Yes, to a certain degree, but it depends upon what information is being viewed and how it is being accessed.

- Can the Cognitive Health Coaching database be ported into Epic?

  - Yes, in that you could probably take certain pieces. For example, you could build flowsheets for patients to enter data manually in MyChart, which would then be available to the clinicians in Epic.

  - No, it would take an enormous effort to get this entire system interfaced directly into Epic and build a UI for interacting with the data.

- What are the business processes for doing so?

  - With respect to Epic as a company, they would need to see a business need to develop or release such an application.

  - For OHSU, it would be a similar process. However, somewhat more attainable than that of Epic. Again this would apply to the parts of the Cognitive Health Coaching database that could be built and operationalized in Epic. Ultimately, our work in ITG is dictated by the need of the organization. For example, if a group (i.e. Sleep Medicine) approached us with a request to give patients the ability to document certain aspects of their sleep habits, we would take the request, run it

> through our change management process, then start working with them to build the needed functionality and workflows."

An interview was conducted with Jeff Jensen on 5/13/10 from 11:00 AM to 12:00 PM. (Jensen, Systems Applications Analyst, 2010) The goal was to glean information regarding the Epic® MyChart interface and reporting capabilities. A test server, consisting of fictitious patient data, was used for the demonstration.

The interface is designed to match the OHSU Health site. Users must accept terms and conditions prior to logon completion. Three key site categories are worth noting:

1. My Health Record (view health information)
    - Current Health Issues
    - Patient chart – pulled directly from Epic:
        - Allergies, medications, immunization, preventive care
        - Health history
        - Growth charts – i.e. "proxy access" to view son's records
        - Vital signs flowsheets (longitudinal chart view of office visit):
            - Chart (table) by date
            - Line graphs

- Track My Health
    - This area is directly related to this Capstone project. Patients can manually enter information into a form while online at home. A flow sheet is generated on the site for viewing. OHSU has a glucometer (nobody using) that can plug in to a personal computer via USB and be integrated with MyChart.
    - Flowsheets
        - Episode Report: view patient-entered data
        - Flow sheet Report
    - Recent Visits: Contains summaries of admissions, ER visits, and out-patient visits.
    - Test Results (text-only for patients in MyChart)
        - Blood, urine, radiology, etc.
        - Manually entered by providers
        - Charts and line graphs are available. Clinicians have essentially the same views; they have requested more robust data representation.

2. Communicate with provider
    - Non-urgent medical questions
    - List of providers dropdown (must have been seen by a particular provider to select – can't just choose anyone)
    - Routed to clinical staff for triage; providers may respond if necessary

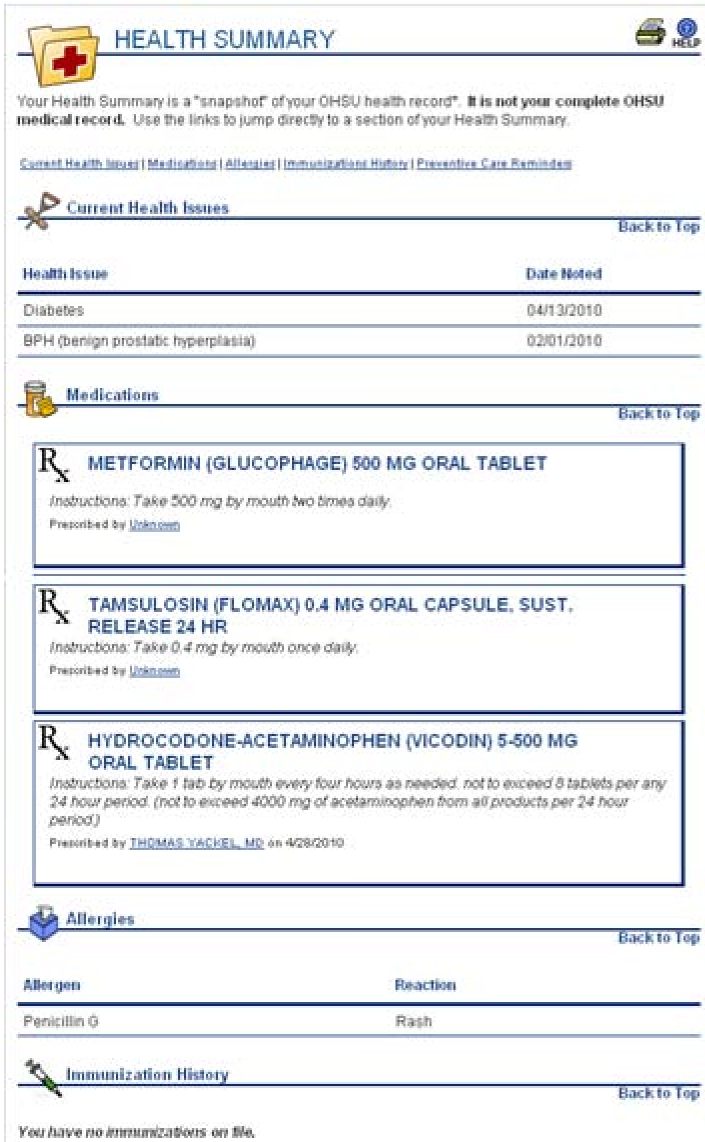
3. Administrative functions

    - Schedule appointments by selecting provider from dropdown
    - Demographics
        - Billing and insurance

Jeff indicated Epic® MyChart was implemented in the ambulatory unit at some time in 2005. Individual clinics were equipped with the system on a rolling basis from 2006 to 2006. Initial clinician resistance was expected and encountered while transitioning from paper to electronic record formats. Some noted negative aspects were related to workflow. Two examples were that workflow was not efficient because the system was designed for primary care physicians versus specialists, and patients now had too much access to clinicians instead of the traditional layer of abstraction. However, users did like the convenience and efficiency of the EHR. Jeff concluded by stating that a full implementation, as opposed to phased, approach might have worked better to limit resistance.

Jeff provided some helpful screen shots from Epic® MyChart (with the company's permission):

Figure 21: Health Summary



HEALTH SUMMARY

Your Health Summary is a "snapshot" of your OHSU health record*. **It is not your complete OHSU medical record.** Use the links to jump directly to a section of your Health Summary.

Current Health Issues | Medications | Allergies | Immunizations History | Preventive Care Reminders

Current Health Issues

Back to Top

Health Issue	Date Noted
Diabetes	04/13/2010
BPH (benign prostatic hyperplasia)	02/01/2010

Medications

Back to Top

METFORMIN (GLUCOPHAGE) 500 MG ORAL TABLET

Instructions: Take 500 mg by mouth two times daily.

Prescribed by Unknown

TAMSULOSIN (FLOMAX) 0.4 MG ORAL CAPSULE, SUST. RELEASE 24 HR

Instructions: Take 0.4 mg by mouth once daily.

Prescribed by Unknown

HYDROCODONE-ACETAMINOPHEN (VICODIN) 5-500 MG ORAL TABLET

Instructions: Take 1 tab by mouth every four hours as needed. not to exceed 8 tablets per any 24 hour period. (not to exceed 4000 mg of acetaminophen from all products per 24 hour period.)

Prescribed by THOMAS YACKEL, MD on 4/28/2010

Allergies

Back to Top

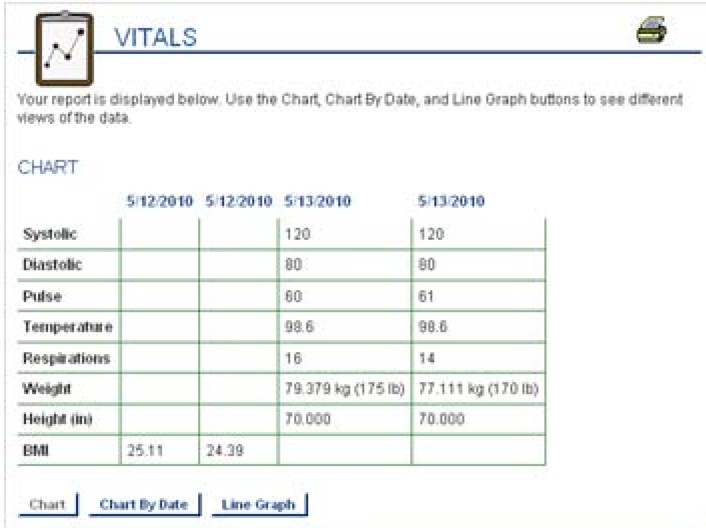
Allergen	Reaction
Penicillin G	Rash

Immunization History

Back to Top

You have no immunizations on file.

Figure 22: Flowsheet Chart



VITALS

Your report is displayed below. Use the Chart, Chart By Date, and Line Graph buttons to see different views of the data.

CHART

	5/12/2010	5/12/2010	5/13/2010	5/13/2010
Systolic			120	120
Diastolic			80	80
Pulse			60	61
Temperature			98.6	98.6
Respirations			16	14
Weight			79.379 kg (175 lb)	77.111 kg (170 lb)
Height (in)			70.000	70.000
BMI	25.11	24.39		

Chart | Chart By Date | Line Graph

Figure 23: Test Result Charting and Graphing

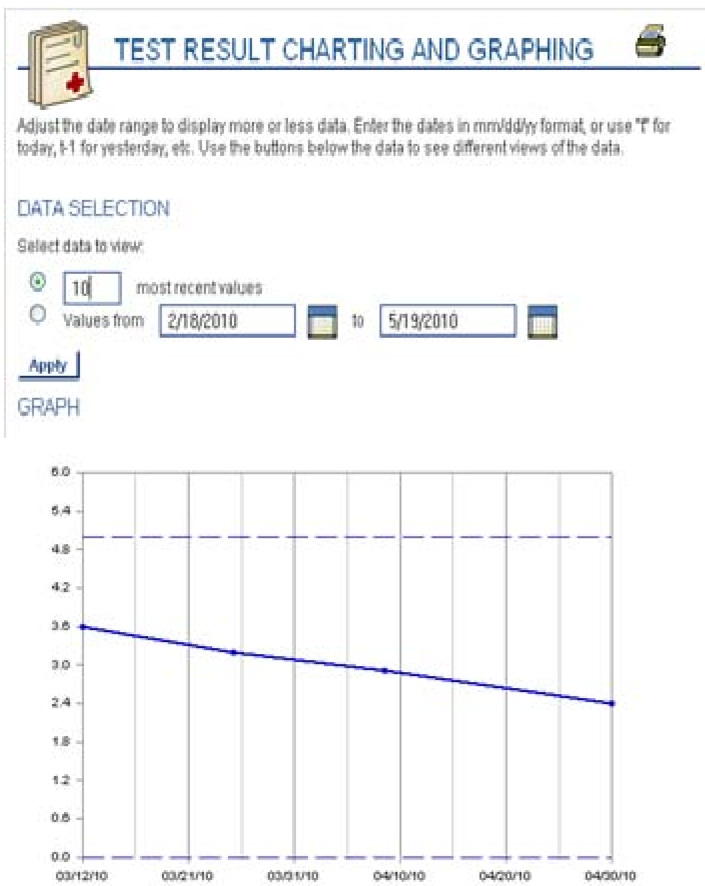
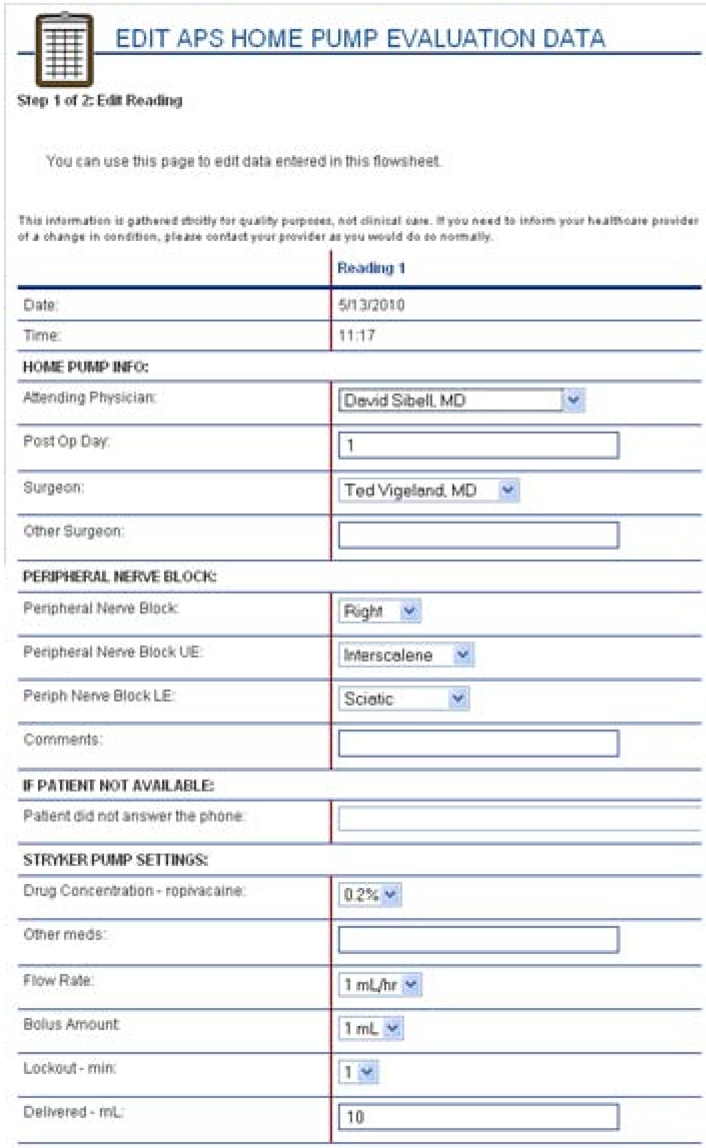


Figure 24: Daily Chart Input Form



EDIT APS HOME PUMP EVALUATION DATA

Step 1 of 2: Edit Reading

You can use this page to edit data entered in this flowsheet.

This information is gathered strictly for quality purposes, not clinical care. If you need to inform your healthcare provider of a change in condition, please contact your provider as you would do so normally.

	Reading 1
Date:	5/13/2010
Time:	11:17
HOME PUMP INFO:	
Attending Physician:	David Sibell, MD
Post Op Day:	1
Surgeon:	Ted Vigeland, MD
Other Surgeon:	
PERIPHERAL NERVE BLOCK:	
Peripheral Nerve Block:	Right
Peripheral Nerve Block UE:	Interscalene
Periph Nerve Block LE:	Sciatic
Comments:	
IF PATIENT NOT AVAILABLE:	
Patient did not answer the phone:	
STRYKER PUMP SETTINGS:	
Drug Concentration - ropivacaine:	0.2%
Other meds:	
Flow Rate:	1 mL/hr
Bolus Amount:	1 mL
Lockout - min:	1
Delivered - mL:	10

Figure 25: Daily Chart Output Form

APS HOME PUMP EVALUATION

HELP

Select number of readings or a date range to view the data you are tracking, and click **Apply**

Add New Data

DATA SELECTION

Select data to view:

10 most recent values

Values from 5/19/2010 to 5/19/2010

Apply

CHART

	5/13/2010 11:17 AM
HOME PUMP INFO	
Attending Physician	David Sibell, MD
Post Op Day	1
Surgeon	Ted Vigeland, MD
Other Surgeon	
PERIPHERAL NERVE BLOCK	
Peripheral Nerve Block	Right
Peripheral Nerve Block UE	Interscalene
Periph Nerve Block LE	Sciatic
Comments	
IF PATIENT NOT AVAILABLE	
Patient did not answer the phone	
STRYKER PUMP SETTINGS	
Drug Concentration - ropivacaine	0.2%
Other meds	
Flow Rate	1 mL/hr
Bolus Amount	1 mL
Lockout - min	1
Delivered - mL	10

Jeff Jensen also offered insightful thoughts relative to EHR summary reporting. They were considered when devising proposed EHR reports in the next section. Flowsheets were a nice touch and were comparable to the dashboard concept. One important note to emphasize is that the Epic EHR charts and line graphs, at least in the OHSU implementation, offered essentially the same views for clinicians and patients. Clinicians have requested more robust data representation.

Proposed Cognitive Health Coaching EHR Summary Reports

Supplementary data analyses were conducted in the master spreadsheet document in an effort to derive EHR summary reports from the PHR examples and input from OHSU staff and researchers. The result was a dashboard summary of outcomes for sleep quality, cognitive performance, and socialization. A common color-coding scheme was utilized to alert clinicians about any problem areas: Green = Good, Yellow = Fair, Red = Poor. These data representations deliver a high-level overview suited to clinicians.

Figure 26: Cognitive Health Coaching EHR Summary Dashboard

		Date Range: 1/1/09 - 1/31/10		
Sleep Quality	Time Asleep	Times In/Out Bed	HR (BPM)	Respirations
	7 Hrs. 17 Mins.	1	75	21
	Goal: 8 Hrs. 0 Mins.	*Goal: 0 (zero)*	*60-80 BPM*	*15-25 RPM*
Cognitive Performance	# Games Played	Game Scores (Up/Down)	PC Session Count	PC Session Length
	676	Down	35	897
	Goal: 600	*Goal: Up*	*Goal: 45*	*Goal: 1200 Seconds*
Socialization	# Phone Calls	Phone Call Length	# Skype™ Sessions	Skype™ Session Length
	2	610	2.5	300
	Goal: 3	*Goal: 420 Seconds*	*Goal: 2*	*Goal: 600*
NOTE: Values are averages.				

For example, the significant decrease in average sleep time (Figure 27) during the month of September could signal an alert. Attributing factors might have been anxiety, post-surgery pain, apnea, etc. Figure 28 provides another example of a steep downward trend in socialization throughout December. Was the patient depressed, disinterested, or simply out of town visiting family? The last reason would eliminate the need for maintenance of normal levels because the patient is visiting people with whom he normally communicates via telephone or Skype™. Regardless, it is the clinician's duty to work with health coaches, caregivers, and family to better understand reasons for noticeable trending spikes in either direction.

Figure 27: EHR Sleep Quality Trending

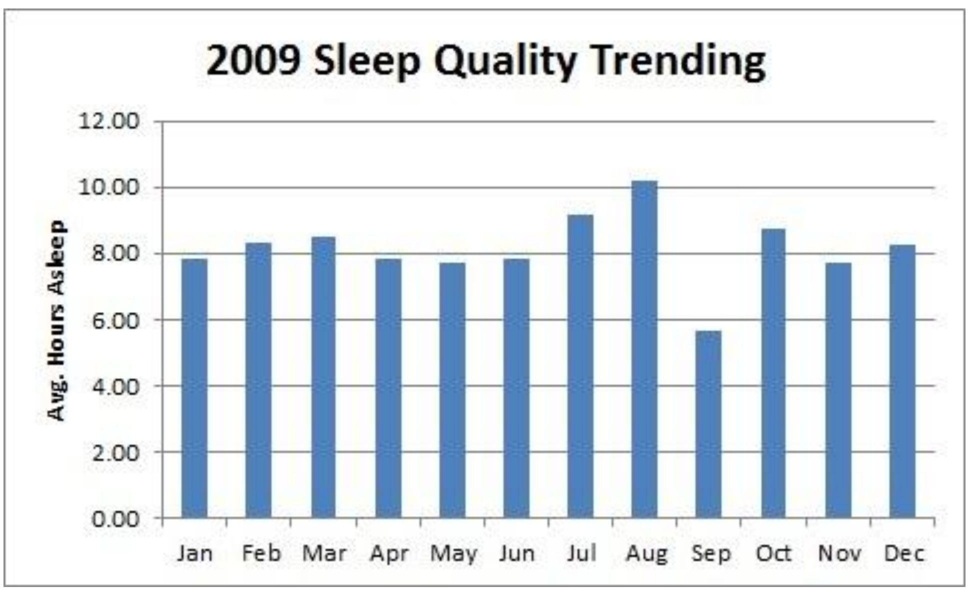
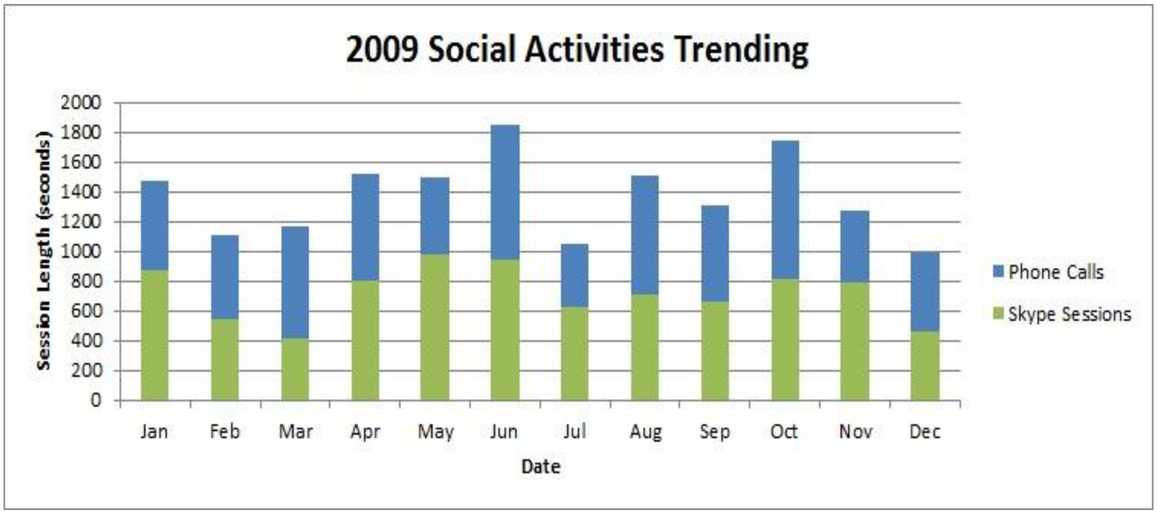


Figure 28: EHR Social Activities Trending



EHR Reports Summary

Based on results from PHR research, templates were presented for select tests in each of the three main study categories: sleep quality, cognitive performance, and socialization. Value can be obtained if the clinician and cognitive health coach coordinate to address noteworthy deviations in a patient's condition. These models will aid the team in developing customized EHR summary reports in the next project iteration if OHSU determines a sound business case is proven by the cognitive health coaching team and resources are made available.

Discussion

Overview

The results garnered in this study provided a foundation for integrating newly defined sleep management, cognitive monitoring and remediation, and socialization summary metrics variables into PHR and EHR systems. One very significant finding was that representation of these new variables could be modeled upon the established IEEE® 11073 Standard, particularly – Part 10471 (Device Specialization – Independent living activity hub), and HL7 Personal Healthcare Monitoring Reports (PHMR) messaging formats. Another important and related discovery to note was that Microsoft® HealthVault™ supports both CCD and CCR message formats; Google™ Health only supports its own version of CCR. Therefore, Microsoft® HealthVault™ should be the PHR chosen for future cognitive health coaching project work. Also, interaction with the various systems and consultation with OHSU staff proved invaluable in drafting proposed summary reports in dashboard and graph formats. Finally, this study revealed PHR and EHR summary data representation was similarly designed in a simplistic fashion from an out-of-the-box perspective. Report capabilities for both types of systems could be enhanced through customization, but the crucial determinant is building a viable OHSU business case.

Standardization and Data Representation

The IEEE® 11073 – Part 10471 (Device Specialization – Independent living activity hub) Standard and HL7 Personal Healthcare Monitoring Reports (PHMR) supply the basis for interoperability and message formats, respectively. IEEE® 11073 contains parts pertaining to physical layer communication between various medical measurement devices: pulse oximeters, thermometers, weighing scales, glucose meters, cardiovascular fitness and activity monitors, strength fitness equipment, and the independent living activity hub. (McCabe, 2008). Part 10471 more specifically applies to devices that are aligned with the current study: cell phones, computers, personal health appliances, set top boxes, etc. (IEEE 11073™ Standard Committee, 2008) Technical details of the communication protocols were beyond the scope of this project but their existence may ease the integration of cognitive health coaching specialized equipment.

The HL7 CDA-based (combined CCD/CCR standard) PHMR can also facilitate future iterations of the cognitive health coaching project. The PHMR is a document that defines personal healthcare monitoring information transmitted as notes and raw data. Some information characteristics may include representation of measurements captured by devices, representation of notes or summaries manually added by caregivers or clinicians, and representation of graphs added by other devices. Constraint-based templates specify and validate agreed-to requirements for exchange. (HL7, 2008) A sleep-management template was drafted in the definitions section of this paper to give the reader a glimpse of how the variable metrics for a patient might appear.

Research showed a major limitation with one of the PHR systems. Google™ Health currently supports only its own version of CCR, while Microsoft® HealthVault™ supports both CCD and CCR message formats. Therefore, Microsoft® HealthVault™ should be the PHR chosen for future cognitive health coaching project work because it adheres to PHMR specifications. Logic dictates the use of a more universal PHR system that will be more compatible with existing EHR systems.

PHR and EHR Summary Report Design

PHR and EHR summary data representation was similarly designed in a simplistic fashion from an out-of-the-box perspective. Microsoft® HealthVault™ measurements were displayed using trending charts and a detailed table, with the option of hiding one or the other. Google™ Health test results were analogous in the representation of data. The Epic® MyChart EHR patient portal incorporated line graphs and flowsheets for longitudinal chart (table) views of office visits. MyChart was constrained in that text-only test results were available. Radiologic images could only be viewed by clinicians using the Epic hospital-based EHR.

Report capabilities for both types of systems could be enhanced through customization, but the crucial determinant would be building a viable OHSU business case. The Microsoft® HealthVault™ Developer Center SDK and the Google™ Health APIs enable customized development of portals to connect with clinical systems. An obvious goal would be the exchange of information between patients, caregivers, health coaches, and healthcare providers. Jeff Jensen's email responses to the group interview questions indicated Epic integration could be possible using similar Epic-based tools. He expounded by stating Epic would need a strong business case to develop such an application and OHSU would have to justify the effort internally through the proper approval channels.

Proposed PHR and EHR Cognitive Health Coaching Summary Reports

Proposed summary reports were designed based on several factors. The nature of each variable was considered in the data representation decision. For example, the many attributes associated with sleep management necessitated a dashboard and stacked bar graph(s) in the PHR setting. Next the audience is taken into account. A health coach may desire select data that may help ascertain an effective cognitive health care plan, while a clinician needs the executive summary in order to make a diagnosis based on physiological and cognitive signs and symptoms. Another important factor is the time period. A graph can be more conducive to trend analysis than a table listing 40 days of results. The combination of traditional research, PHR practical application, personal interviews, and email communication helped formulate the final PHR and EHR cognitive health coaching summary reports.

Metrics and summary reports for each variable could potentially impact the biomedical informatics field in positive ways. Sleep management might be used to detect whether there are any abnormal patterns that should be addressed by health coaches or clinicians. Data may infer cognitive conditions or other serious problems, like sleep apnea.

Cognitive monitoring and remediation metrics summaries may prove significant relative to daily values and variability of memory, divided attention, planning, verbal fluency, motor skills, etc. Care plans and protocols could be catered to individual needs. Finally, socialization reports can delve into social interaction levels to determine if patients have isolated themselves or if they are actively engaged.

Summary and Conclusions

This paper investigated integrating new cognitive health coaching monitoring and behavioral summary metrics variables into standard personal health record and electronic health record systems. These variables were focused in three primary study categories of study involving sleep management, cognitive health monitoring and remediation, and socialization. Three specific aims were asserted from the onset: 1) Define the new monitoring and behavioral summary metrics variables, and their respective elements. 2) Research PHR systems to develop standardized summaries of data from the three key variables. 3) Consult with OHSU staff to understand which summary reports from the PHR might be relevant and useful to clinicians using EHR systems. The study also briefly discussed the possibility of utilizing consulting companies, such as Lamprey Networks and IBM, to map data from various devices (e.g., bed mats) to PHR and EHR systems.

There were several important conclusions resulting from the research project, which are reiterated from the discussion section. One very significant discovery was that representation of these new variables could be modeled upon the established IEEE® 11073 Standard – Part 10471 (Device Specialization – Independent living activity hub) and HL7 Personal Healthcare Monitoring Reports (PHMR) messaging formats. Another important and related finding to note was that Microsoft® HealthVault™ supports both CCD and CCR message formats; Google™ Health only supports its own version of CCR. Therefore, Microsoft® HealthVault™ should be the PHR chosen for future cognitive health coaching project work. Also, interaction with the various systems and consultation with OHSU staff proved invaluable in drafting proposed summary reports in dashboard and graph formats. Finally, this study revealed PHR and EHR summary data representation was similarly designed in a simplistic fashion from an out-of-the-box perspective. Report capabilities for both types of systems could be enhanced through customization, but the crucial determinant is building a viable OHSU business case.

Resultant findings indicated assorted data representation formats of the new summary metrics variables should be employed and catered to the respective summary reporting preferences of health coaches and clinicians. PHRs should employ traditional tables, graphs, and a dashboard in one instance (sleep quality), but focus on specific data better understood by cognitive health coaches and family members of patients. EHRs should rely primarily on a very high-level dashboard format. Some trend analysis graphs can be effective if the period is long-term (e.g. one year segmented by months) and proper scaling is configured to show marked change.

These stakeholders could use the data to develop effective and timely care plans. Sample reports were made available to the OHSU Cognitive Health Coaching team for future implementation into a test or production infrastructure. Ultimately the desired outcome of this work is to assist patients in living relatively independent lives and maintain a sense of dignity during the aging process.

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Appendices - Supplementary Data Integration Research

The supplementary data integration research section can be leveraged in future iterations of the parent OHSU Cognitive Health Coaching Project. For example, Lamprey Networks (LNI) and IBM may be able to customize software code that can port non-Continua® device data into PHRs and EHRs. Such services would be useful considering the novelty of metrics variables and the devices used to collect raw data.

Appendix A: Lamprey Networks

Organization: Lamprey Networks, Inc.
Web Site: http://lampreynetworks.com/
Interviewee: Barry Reinhold (Reinhold, 2010)
Interviewer: Tony Grecco, OHSU MBI Student and Intel Employee
Date: 3/5/10

Interview Questions – Personal Healthcare Monitoring (PHM) Reports Project

1. From Rick Cnossen's introductory email, it would be useful to have the capability to take Continua-based data and send it to PHRs (similar to what you have demonstrated with your HealthLink Web Service sending data to PHRs and EHRs). (HealthLink, 2010) Are there any options, or is there a specific process, to make this capability available for said research (e.g., research grant, open source code, licensing, pay per byte)?
    - Developing technology to tie people to Continua® data migration into PHRs/EHRs
    - HealthLink is based on the Continua device stack (IEEE 11073/20601); may have to customize for our specific; map to SNOMED and LOINC
2. Do you have white papers or other documentation that would provide an overview of your service offerings?
    - Work is conducted on a contract basis: customer provides RFP or SOW
    - Barry may have a template or sample document; email to follow
3. Do you support CCD and CCR?
    - Microsoft® HealthVault™ and Google™ Health
    - Map into PHMR for standardized processing
    - How to read device? How to map into PHMR?

4. What have been your primary challenges or roadblocks?
    - Understanding what kind of data is going to be migrated
    - Knowing Microsoft® HealthVault™ requirements for unique devices
5. Do you have any recent success stories?
    - Barry said he would provide customer references and/or case studies
6. Do you know of specific contacts, particularly those using your software and services, who might be willing to attend a one-hour interview session with me?
    - The interviewee advised inquiring with Rick Cnossen from Intel.

The following material is taken directly from LNI's subsequent email:
"LNI is a provider of technical services related to interoperability. Few organizations know how to address the full range of issues that face an industry association bringing standards based technology to market. LNI's mission is to address the interoperability problem. LNI has the experience, engineering know how, and execution skills to not only manage technical testing and certification processes, but to design and implement standards based networks protocol software stacks. This combination of experience, management and engineering resources allows LNI to:

Provide consultative and execution services.

- Design software stacks and drivers for network protocols.
- Provide technical expertise on standards.
- Validate test results, and resolve concerns that arise in certification and logo programs.
- Organize and run Plugfests.

- Provide support services for organizations writing standards.
- Identify the testable items in a standard, and evaluate the effort required to create conformance tests for those items.
- Implement test systems and test infrastructure.

LNI employees have led industry initiatives, developed software, authored test suites and created test tools for numerous organizations including Advanced Switching Interconnect, Digital Living Networks, Open Fabrics Alliance, InfiniBand™ Trade Association, iWARP (RDMA over IP) Consortium, Fibre Channel Industry Association, and the PCI-Express SIG.

LNI has created infrastructure tools and methods that enable it to work with standards that are still in flux. This allows LNI to understand the requirements of a specification and to design software that will work throughout the lifecycle of a technology. LNIs early work with emerging technologies is a key ingredient to eliminating interoperability issues before products reach market.

LNI has demonstrated proven expertise in managing large development efforts on many scales. Recently LNI has completed its second contract with DLNA to identify, author and implement a test tool for Version 1.5 Guidelines. The test tool is built on top of LNI UPnP Core SDK. This SDK is at the heart of the DLNA certification program that is being used around the world by independent test labs and DLNA product vendors.

LNI is the original developer of CESL code, providing initial Reference Devices (10 Agents and one Manager)."

Appendix B: IBM

Organization: IBM
Web Site: http://www.ibm.com/us/en/ ;
http://www.ibm.com/smarterplanet/us/en/healthcare_solutions/ideas/
Interviewee: Rich Rogers, Senior Technical Staff – Healthcare Standards IBM Software Group
Interviewer: Tony Grecco, OHSU MBI Student and Intel Employee
Date: 3/15/10

Interview Questions – Personal Healthcare Monitoring (PHM) Reports Project

1. From Rick Cnossen's introductory email, it would be useful to have the capability to take Continua-based data and send it to PHRs (similar to what you have demonstrated with your Web Service sending data to PHRs and EHRs). Are there any options, or is there a specific process, to make this capability available for said research (e.g., research grant, open source code, licensing, pay per byte)?

   Summary:

   - Not in device/gateway space like Continua
   - IBM is at RPM server level in PHR-EHR Communication Process figure
     - Collect data from gateways
     - Complex event processing, rules engines
     - Integration into PHRs/EHRs, Chronic Disease Management systems
     - Make information meaningful for primary-care physician or specialist via HIE

2. Do you have white papers or other documentation that would provide an overview of your service offerings?

    - Patient-Centered Medical Home: model for primary care (accountable care organizations) reimbursement
    - Paradigm Now: fee-for-service is not conducive to good health

3. Is there a specific IBM URL for healthcare?

    - www.ibm.com/healthcare
    - http://www-935.ibm.com/services/us/gbs/bus/html/bcs_healthcare.html
    - www.pccg.org

4. Do you support CCD and CCR?

    - Continua uses HL7 CDA and constrains for particular users
    - Refer to PMHR DSTU (HL7, 2008)

5. CCD seems to be the standard of choice in the U.S., for myriad EHR vendors, and the HL7 PHM Reports Project. Since Google™ Health is predicated on CCR, would it be more prudent to concentrate on Microsoft® HealthVault™ (CCD and CCR)?

- The interviewee was under the impression Google was using its own CCR implementation called CCR-G; plan to support CDA

6. Is there any general advice or guidance you can impart?

    - Performed a demo with Lamprey Networks at trade show earlier in the year
    - Epic and other EHR vendors have their own application programming interfaces (APIs)
    - Open Source organization (program - HIE profiles): www.openhealthtools.org

7. What have been your primary challenges or roadblocks?

- Industry is not quick to adopt technology
- Security and privacy concerns
- Continua – regulatory concerns (FDA) and liability
- Who is going to pay for these solutions?

8. Do you have any recent success stories?

    - VA VistA system: correct reimbursement system

9. Do you know of specific contacts, particularly those using your software and services, who might be willing to attend a one-hour interview session with me?

    - The interview was not able to provide any contacts. He stated that a potential for engagement or a value proposition would likely be needed for someone from the sales team to provide more information on services.

Appendix C: Dossia

Dossia is a consortium of U.S. employers banded together to provide a PHR for their respective employees. Member organizations include Intel Corporation, Wal-Mart, Applied Materials, AT&T, British Petroleum (BP), Cardinal Health, Pitney Bowes, Abraxis BioScience, Inc., Vanguard Health Systems, and Sanofi-Aventis. According to professional protocol, I am now disclosing that I work for Intel Corporation. Dossia's initial focus is an employee-based PHR but the ecosystem will likely evolve to adopt the broader consumer market. The company could potentially become an alternative to Microsoft® HealthVault and Google™ Health.

I have been a Dossia PHR pilot user over the past several months. Representatives have expressed interest in discussing a potential collaboration relative to my OHSU project. The details may extend beyond the scope of this study because the current ecosystem only includes employees, not independent consumers.

Excerpts from Dossia presentation to Intel Corporation employees (Welcome to My Personal Health Record Q&A Session, 2010):

Vision

Dossia's vision is to transform U.S. healthcare empowering individuals to take better control of their health and healthcare.

Strategy

- Consortium of US employers building a system for employees
  - Employees are entitled to copy of their data under HIPAA and ARRA (Stimulus Bill)
- Provides personal control to the employee
  - Backed up by a commitment to real privacy and security.
- Creates a national personal health platform
  - Dossia is the data repository; open API is the real enabler
- Creates a lifelong, personal, private, portable dataset
  - Complete and independent view of the patient information. Employees will invest their time in something durable
- Independent non-profit utility – Dossia Foundation control
  - Dossia will not rely on tolls, lock-in, advertising, search

Revolution

- Employer Leverage – informed employees critical to employer leverage over health plans and providers
- Reduced Spending – empowered employees become effective healthcare consumers
- Delivery Innovation – connected community allows employers to demand virtual integrated delivery
- Platform Independence – un-tethered from and not competitive with the key actors in healthcare

Personal Health Applications

- Variety of Personal Health Tools
- Monitor your health habits
- Track health metrics
- Significantly improve your own well being and reduce risk of health issues down the road

Appendix D: Email from Dr. Bill Herzberg

Dr. Herzberg offered insightful thoughts on "unobtrusive monitoring of the elderly at home" (Herzberg MD, 2010). Spelling and grammatical errors were not corrected in order to retain the integrity of this message.

> "Today I attended a series of lectures by Alan Pack MD (a sleep specialist from U Penn pack@mail.med.upenn.edu). I posed the following question to him, "In the healthy elderly, what elements of sleep structure are predictive of cognitive decline?" To paraphrase his answer, although normal aging may entail some loss of sleep efficiency, loss of slow wave sleep and sleep fragmentation, sleep disturbance is an early manifestation of neurodegenerative dementias. REM behavior disorder is predictive of Parkinsons disease years later. There are only rare instances of REM behavior disorder brain autopsies without alpha-synuclein pathology. In senile dementia Alzheimers type, sleep disturbance is also an early manifestation of dementia with sleep fragmentation and breakdown of circadian control resulting in daytime naps and wandering at night. [Disturbed sleep is the most common reason people with SDAT go to nursing homes.] In a drosophila model of SDAT, sleep changes predate memory changes. In mice, sleep deprivation provokes cellular stress. In older mice, sleep deprivation upregulates pro-apoptotic processes accelerating degenerative disease. In disorders which preferentially decrease REM sleep (such as obstructive sleep apnea) loss of REM may interfere with the consolidation of memory. Any cause of recurrent sleep interruption will cause neurocognitive abnormalities ie. excessive sleepiness, but in sleep apnea, both interruption of sleep and recurrent hypoxia cause

neurocognitive abnormalities. Interrupted sleep will cause cognitive changes in the short term, recurrent hypoxemia and resulting brain injury in particular to wake active neurons in locus ceruleous may cause sleepiness not correctable with CPAP. (The mesial temporal lobes hippocampus instrumental in memory acquisition are also particularly sensitive to recurrent hypoxemia.) Indirect effects of sleep apnea, such as insulin resistance, cardiac dysrhythmias, atherosclerosis, hypertension can obviously result in stroke/vascular dementia. Many of these changes are thought mediated more by oxidative stress and increased inflammatory state causing atherosclerosis rather than sympathetic activation, but many factors are involved.

In a discussion on the consequences of sleep deprivation, Pack listed the following: 1) wake state instability leading to performance lapses, 2) altered cognitive processing, 3) fall asleep (car) crashes and 4) metabolic consequences a) insulin resistance and b) increased appetite. An interesting table on fall asleep car crashes (a surrogate of performance lapses and altered cognitive processing) gave the following increased risks in the form of odds ratios:

night shift work	6-12
sleep duration<5 hours	5-7
Epworth score 11-15	3-4
Epworth score >16	6-15
hours awake before crashing 15-20 hours	9
>20 hours	57 (!!!)

How does this impact your study? We can get a good sense of 1) duration of sleep in bed corresponding to motionless time in bed 2) time onset of sleep 3) time offset of sleep 4) sleep efficiency 5) frequency of arousals from sleep and 6) perhaps apneas. Without EEG, muscle tone, eye movement data we can't definitely score REM versus NREM sleep, but we can predict REM based on irregular heart rate, irregular respiratory cycle and SWS (slow wave sleep or deep NREM) based on regular heart rate and respiratory rate and arousals based on motion plus irregular HR and RR. I would anticipate worse cognitive function during the afternoon circadian lull (siesta time) and this lull would be more pronounced in the sleep deprived. After accounting for circadian phase, alertness and cognitive performance would decline as a function of time awake and again would be worse in those most sleep deprived. We will need to monitor ambient light (especially in the blue part of the spectrum) and record cognitive testing times and relate to hours awake, sleep deprivation and circadian phase. I imagine you would need to account for learning curves with the cognitive tests.

There is a lot of variability in sleep parameters in the elderly, so it may be more useful to compare subjects to their own baseline rather than normative data.
I think it's easy to drown in too much information or information which is ill displayed. (I am a big fan of Edward Tufte's Visual Display of Quantitative Information and his other books which I can lend out.) I would display information over time graphically ideally summarizing sleep, mobility, cognitive function, socialization, metabolism by single numbers. I would generate a sleep number based on deviation from baseline sleep efficiency, arousals, total sleep time, sleep phase and perhaps subjective sleep quality and daytime sleepiness. If this number changes I would allow the viewer to expand the number into its various components interactively rather than always displaying all the data.

I know caloric intake is very hard to quantify, but we are already getting daily weights from the bed (true?) and most rapid weight changes relate to fluid status, meals and BMs. So if we measure hydration status (perhaps with urine specific gravity, urine osms) we could distinguish caloric failure to thrive from dehydration, caloric weight gain from fluid retention. I think a fall sensor would complement gait velocity nicely to generate a mobility number. Steve Chamberlain sac@pobox.com has a fall sensor which I believe uses a microphone plus accelerometer (I don't know how obtrusive), velocity sensors based on an array of infrared beams. His system is being set up in a nursing home."