UMD/HCIL Consumer Health Informatics Workshop

WHEN: Friday, May 30, 2008

WHERE: Computer Science Instructional Center, Room 3118
University of Maryland
College Park, MD 20742
U.S.A.

Organizers: Dr. Bo Xie & Dr. Derek Hansen
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SCHEDULE

8:30 AM: Registration/Breakfast

9:30 AM – 9:50 AM: Introduction

Session 1: Designing e-Health Information Web Sites

9:50 AM – 10:15 AM
Delivering tailor-made health information on the Internet via personalization and contextualization

Laurence Alpay PhD, John Verhoef PT PhD, Bertie Zwetsloot-Schonk MD PhD
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Although the Internet offers unlimited possibilities for finding health information, website visitors in particular older people, often encounter several challenges. This includes, for example, finding the information/health resource which is directly relevant to their situation, and which takes into account their level of health literacy and understanding of the healthcare information. From this perspective, there is a strong need for delivering tailored e-health information. This tailoring can be viewed as twofold: 1) Personalization such as language preferences, cultural criteria, and taking into account someone’s health situation; 2) Contextualization as supportive information such as background information and explanation of medical terms.

A lack of tailored e-health information inevitably affects communication between the citizens/patients and the healthcare professionals. Efficient communication which insures that the health message is understood and which take into account the person’s preferences and own health situation is a challenge for the website designers and the health professionals. We report here on a study which addresses this issue, using a theoretical model of communication whose central theme is that of context. A randomized controlled experimental design was chosen, using as a test-bed a website targeted at the older population in the area of fall prevention we previously developed. Participants (n=40) were randomly assigned to exposure or no exposure to contextualization with the information on the website. Results showed that 1) contextualization increases understanding for non-knowledgeable users in the field of fall accidents, 2) participant’s cognitive style is a significant factor on understanding and 3) participants brought their own contexts (e.g. social and psychological contexts) to support their understanding.

This study has relevant implications for designing websites with functionalities of personalization and contextualization, and is seen as a step towards developing guidelines as part of the design requirements for tailor-made health websites.

10:15 AM – 10:40 AM

Evaluating the Effect of Usability Testing on an eHealth Tool for Clinical Trials Recruitment

Nancy L. Atkinson, Ph.D., Holly A. Massett, Ph.D., Lauren McCormack, Ph.D. Farrah Darbouze, MPH, Christy Mylks, & Bradford Hesse, Ph.D.

Clinical trials are an essential process in the fight against cancer. New ehealth tools have been developed to facilitate the information seeking and decision-making of women with breast cancer who are considering whether to participate in cancer clinical trials. Based on previous usability testing research, an Internet-based clinical trials recruitment service was redesigned to improve the user experience and the acceptability of the application. The purpose of this study was to compare the site’s original interface and functionality to the redesigned site. Women who had a breast cancer diagnosis within the last 5 years were recruited to participate in the study. Participants (N=74) were randomized into two groups: one group used and reviewed the original site first followed by the redesigned site, and the other group used and reviewed the sites in reverse order. After reviewing both sites, participants were asked to indicate which version they preferred and met their needs and expectations better. The findings demonstrated the value of
responding to usability testing results to facilitate the success of programs and interventions. The study has implications for important considerations in conducting relevant usability testing methods with complex eHealth tools and systems.

**10:40 AM – 11:05 AM**

**Usability Testing of a Prototype Google Maps Web Site to Locate and Evaluate American Nursing Homes**

Authors: Glenn Pearson, Ph.D. - Senior Software Developer*
          Rivka Yerushalmi, MSW – MLS Graduate Student (field study*)
          Bo Xie - Assistant Professor, University of Maryland

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Finding a nursing home for oneself or a loved one is difficult. There can be many homes to choose from locally, with over 16,000 nationwide. Trustworthy, uniform, nationwide information to quickly determine home quality and capabilities is most helpful.

An important source for home quality data is the Centers for Medicare and Medicaid Services (CMS). All federally-funded nursing homes must meet requirements mandated by CMS and administered by individual states. This includes a standard quarterly home-staff assessment of each resident. From this are derived certain metrics for the facility - for example, *the percentage of long-stay residents physically restrained in the last 7 days* - that should reflect the quality of care delivered, not just the residents’ demographics. Other data reported by each home include staffing hours of nurses and aides per resident, bed count, and home ownership type. CMS also mandates roughly annual state inspections, with detailed reporting of healthcare and fire safety deficiencies.

This information is available from CMS’s “Nursing Home Compare” web site in tabular form. While allowing some comparisons, it is not ideal as a quick screening tool.

For faster screening by location and quality, NLM is developing an alternative interface to this data (and derived scoring and ranking). Currently in alpha prototype form, our “Nursing Home Screener” portrays home quality as iconic markers on a Google Map in any of four categories: staffing, fire safety deficiencies, healthcare deficiencies, and care quality inferred from residents’ health. Ranking options can be tailored, and homes with less interesting attributes hidden.
Recently, a first round of field usability testing has been conducted by collaborators at UMCP and RIT. The main findings of testing with middle-aged adults and seniors will be discussed, and some implications drawn for further evolution of our site before it goes public.

Break (10 minutes)

**Session 2: Using e-Health Information Web Sites:**

**11:15 AM – 11:40 AM**

**Participatory Medicine**

Susannah Fox, Associate Director, Pew Internet & American Life Project
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The Pew Internet Project's current estimate is that about 75% of adults and 95% of teenagers in the U.S. go online. Half of American adults have broadband access at home. 75% of American adults have a cell phone and many are using their cell phones to connect to the internet. 80% of internet users look for health information online (we have come to call them "e-patients") and their first stop is usually a search engine. However, most internet users with an urgent health question turn first to a professional for advice. This stands in sharp contrast to how internet users address questions related to education, taxes, Medicare/Medicaid, changing job status, or Social Security. For those topics, the internet or a government agency played much more important roles than did professionals. In this talk, I will explore trends related to the information-seeking behavior of health consumers, social media applications, and participatory medicine.

**11:40 AM – 12:05 PM**

**Data Sources on Trends in the Health of Older Americans from the National Center for Health Statistics**

Yelena Gorina, National Center for Health Statistics, yag9@cdc.gov, Statistician

With number of persons age 65 and over growing at unprecedented rates, the demand -- from legislative authorities to the general public -- for health information on this population is increasing. The purpose of this presentation is to familiarize the audience with sources of data on aging at the National Center for Health Statistics (NCHS). Almost every data system at NCHS includes information on the older population. During the session we will review major sources such as the National Vital Statistics System, the National Health and Nutrition Examination Survey, the National Health Interview Survey, the National Health Care Surveys, the Behavior Risk Factor Surveillance System, and on-line NCHS products and publications on aging-related topics. We will show examples of data requests received from users of the Trends in Health and Aging (THA) website (www.cdc.gov/nchs/agingact.htm) in the last few years. As an example of the data available on the THA website, we will review data from several tables on diabetes in the
older population. In addition, the audience will learn about NCHS plans to combine the Trends in Health and Aging web-site with the NCHS web-site "Health Data for all Ages" (http://www.cdc.gov/nchs/health_data_for_all_ages.htm). The new website will be called “Health Data Interactive”.

12:05 PM – 12:30 PM

**Influence of Computer Training on Older Adults’ Use of NIHSeniorHealth and MedlinePlus Web Sites**

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Data were collected during September 2007—May 2008 in branch libraries of the Prince George’s County Memorial Library System, Maryland from 110 older adults (56-85 yrs., M=69.6, SD=8.1) who participated in computer training classes, which focused on using the NIHSeniorHealth and MedlinePlus Web sites to find health information. The majority of participants was female (73%), African American (53%), and had none or limited prior computer/Internet experience. All participants completed a pre-training questionnaire measuring experience with and knowledge about computers and the Internet, attitudes towards computers, and demographic characteristics. Eighty-nine participants completed a post-training questionnaire measuring experience with and views of the training procedure and curriculum, usefulness and usability of the NIHSeniorHealth and MedlinePlus Web sites, healthcare-related behavioral changes, self evaluation of learning outcome, and attitudes towards computers. Findings indicated that, participants were overwhelmingly positive about the length (80%), frequency (83%), size (83%), and student/instructor ratio (96%) of the training classes, while wishing the duration of training were longer than 4 weeks (67%). The majority of participants found the NIHSeniorHealth (68%) and MedlinePlus (69%) Web sites easy or very easy to use, and the information found on these sites was useful or very useful (96% for NIHSeniorHealth and 85% for MedlinePlus). Twenty-one percent of participants had taken information learned in the classes to discuss with their healthcare providers at least once during the course of training, and another 48 percent of participants plan to do so in the near future. The training had changed the ways participants taking medicine (43%) or making decisions about a health- or medically-related issue (70%). An overwhelming majority of participants reported that they had learned a lot from the training classes (95%), and that they would recommend this course to age peers (99%). Finally, the training had significant positive impact on participants’ attitudes toward computer technology.

Lunch: 12:30—1:30 pm
Session 3: e-Health Communication Applications & Communities

1:30 PM – 1:55 PM

MyCareTeam: Internet technology to improve health outcomes and provider-patient communication in the management of diabetes
Betty A. Levine, MS, Georgetown University medical Center, Washington DC

For a person with diabetes, best practices for managing their disease is a life time endeavor requiring a rigorous regimen of blood sugar and other clinical testing, medication management, nutrition, and exercise. For a healthcare provider, treating a person with diabetes is time consuming and relies on current, complete, and accurate information provided by the patient.

Internet technologies are ideal for bridging the gap between people with diabetes and their health care providers to form a team to manage the disease efficiently and effectively. MyCareTeam, a web based diabetes management application, gives control to a person with diabetes to manage their disease with support from healthcare providers.

With MyCareTeam, one can directly transfer blood glucose readings from a glucose meter to a secure database accessible via the Web and share that information with healthcare providers and others who provide support. Blood pressure and exercise logs are used to track other important measures used in their care along with the display of laboratory results and medication adjustments. Secure messaging lets the person with diabetes communicate with his/her support network on issues related to managing and living with diabetes.

MyCareTeam has been successfully implemented in many communities and cultures as measured by an improvement in clinical outcomes including the reduction in HbA1C, a proxy measure of long-term glycemic control.

This presentation will include information about connecting to multiple monitoring devices, the types of secure communications used within the application, the features required for tracking one’s clinical progress along with results from our implementations. It will also include a discussion of our future plans to grow the MyCareTeam application into a social community where people can expand their support networks to include individuals outside of their immediate support team.

1:55 PM – 2:20 PM

Social Sites for Social Good: CDC's Experiences in Web 2.0
Sanjay J. Koyani, Director, FDA Web Communications, U.S. Food and Drug Administration
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CDC's National Center for Health Marketing views Web 2.0 as "second generation" web that focuses on community/collaboration, user-generated content, and the technology/applications that help users do those things. NCHM sees eHealth and communication technologies as huge opportunities to communicate health and safety information how, when, and where our users
want that information. With CDC's diverse audiences, there's a need for multiple approaches including mobile applications, social networks, widgets/gadgets, and many other tools.

This presentation will describe:

* Why CDC is involved in Web 2.0
* CDC's 2.0 e-health efforts, from ecards and mobile applications to egames and content syndication
* CDC’s research-based approaches to Web 2.0
* Lessons learned during the experimentation process

\[2:20 \text{ PM – 2:45 PM}\]

**Automatically Generated Custom Spreadsheets for Emergency Preparedness Planning Models**

Jeffrey W. Herrmann, University of Maryland
Rachel Abbey, Kay Aaby, Montgomery County, Maryland Advanced Practice Center

Montgomery County, Maryland, is home to one of eight Advanced Practice Centers (APCs) for public health preparedness and response. The APCs customize and package innovative tools for other local public health agencies to strengthen their emergency preparedness planning and response capabilities. In 2004 Montgomery County APC entered into a partnership with the Institute for Systems Research at the University of Maryland to empower local public health departments to use computer models to improve and evaluate their dispensing and vaccination plans to better serve the population during emergencies.

Emergency preparedness includes carefully planning mass-dispensing and vaccination clinics or points of dispensing (PODs). When clinic operations begin, the health department must assign the correct number of workers to various positions. It must also consider the capacity of each clinic (i.e., the number of residents that it can serve per hour) and the number of minutes that residents will spend in the clinic (i.e., time in system, flow time, and throughput time). Clinic capacity affects the number of clinics needed and the total time needed to vaccinate an affected population. The time in system affects the number of residents who will be inside the clinic waiting for treatment; too many residents in the clinic may cause crowding and confusion.

We developed mathematical models to estimate POD capacity planning and queueing to support emergency preparedness planning activities. In order to distribute these models to people with minimal knowledge of mathematical models and no resources for acquiring and learning new software, we developed a spreadsheet application. This allows users with no experience, to create and use customized, analytical capacity planning and queueing network models. Developing spreadsheets for this type of application differs significantly from end-user modeling and typical spreadsheet applications. Public health emergency preparedness planners from around the country have downloaded the software from our website.
Online patient support groups are one of the most enduring legacies of the early Internet days (Ferguson, 1996). They are a testament of the human capacity to generate social context and meaning across time and space, even among strangers in a world of mere text. Traditionally, online support groups have performed their work via asynchronous, threaded conversation in the form of email lists or online forums. This basic conversational structure has enabled members to share information and social support in a highly personalized and empathetic manner (Preece 1999; Galegher et al. 1998). This disease-specific information and support from peers helps individuals better cope with, and make sense of their medical condition – needs that are especially pertinent to those with chronic conditions (Ferguson, 2007; Rimer et al., 2005).

Despite the successes of threaded conversation, many patient groups have supported the creation of additional information resources such as websites and FAQs to help educate information seekers, attract new community members, keep each other up-to-date, and advocate for their disease. Web-based collaborative authoring tools such as wikis provide a new means by which patient groups can collectively create these more durable information resources. This new form of community-based authoring has the potential to spread out the work and encourage new forms of useful participation – things that are vital to patient groups with limited financial resources and a volunteer workforce. However, to be successful, patient groups must overcome the significant social and technical barriers of introducing a new technology to a community. Although wiki-based repositories have been found successful in technical support communities (Hansen 2007; Hansen et al. 2007), their usefulness and viability in a patient support community has not been demonstrated.

In order to understand the potential opportunities and challenges of patient-based collaborative authoring, we performed an action-research field study of 3 patient-support communities. Each community was provided with a customized wiki, along with suggestions on how to best introduce it to the community and integrate it with existing threaded conversations. Suggestions were based on a study of a successful technical support community and tailored to the medical context (Hansen 2007). Data from discussion archives, wiki page histories, and server logs were collected and analyzed along with interviews and conversations between community members and the investigators. Specific research questions that are addressed include:

- What are the social and technical challenges of collaborative authoring by a patient support group?
- What strategies are successful in overcoming those challenges?
- How does collectively created wiki content differ from content generated in the patient discussions or found on official community websites?

Snack break ~3:30pm
3:30-4:30 pm: Discussion/Wrap-up