

Panel:

Can the Health Informatician Help Seniors Cross the Digital Divide?

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Summary

The Internet has become an essential resource for health information that seniors must access if they are to navigate the changing healthcare environment successfully. Yet much of this information is not well designed for seniors. Further, many otherwise disadvantaged seniors are also on the wrong side of the "digital divide," which threatens to exacerbate disparities in their health status. This panel focuses on the role informaticians can play in improving the quality and accessibility of health information available as well as their role in health information outreach to the underserved.

Bern Shen brings a futures perspective to the economic and social impacts of the demographic changes ahead. Susannah Fox reports on the social impact of the Internet, particularly consumers' pursuit of health information online and the specific patterns of use among older Americans. Sara Czaja reports on her extensive research examining the impact of age-related changes in cognition on the performance of technology-based tasks. David Kaufman and Maxine Rockoff describe their work in helping community-based organizations become health information resource centers for disadvantaged seniors.

Keywords: *Internet, Cognition, Seniors, Health Information Seeking, Consumers, Community-Based Organizations*

Topic

The Internet is increasingly becoming the principal source of information for individuals in managing many aspects of their own health care. Seniors are not excepted, as illustrated by the heavy use HHS made of the Internet in rolling out Medicare Part D: repeatedly, the print materials were erroneous or out of date and CMS's policy for making correct materials available was to post them on the web. However, accessing health information for decision-making presents formidable challenges to many seniors.

Questions the panelists will address include:

- Will consumer-driven health care exacerbate health disparities, especially for seniors?
- What are the patterns of Internet use among seniors as a function of age? Will Baby Boomers render the "grey divide" obsolete?
- How can cognitive research help us teach people to access and use online health information?
- Is there a role here for community-based organizations? Can informatics help them?

Panel Participants

Maxine Rockoff – Reaching Underserved Seniors through Community-Based Organizations

Dr. Rockoff is an Adjunct Associate Research Scientist in the Department of Biomedical Informatics at Columbia University. Formerly the Director of the Division of Information Management at The New York Academy of Medicine, she is the principal investigator on an NLM-funded project to provide seniors with access to health information in the supported environment of community-based organizations. She pioneered in "wiring up" New York City settlement houses in 1993 and she co-chaired an NLM Symposium on Community-Based Health Information Outreach in 2004.

As the Internet becomes an essential tool for managing one's own health care, the digital divide threatens to exacerbate the "health status divide." Therefore we need to develop a comprehensive approach for assuring that disadvantaged seniors are provided with appropriate support in accessing health information. Community-based organizations are promising partners for reaching disadvantaged populations because they provide a wide range of programs and services to which classes in finding web-based health and healthcare information could be added.

Dr. Rockoff will moderate the panel and report on some of the challenges and issues involved in partnering with community-based organizations for health information outreach.

Bern Shen – A Futures Perspective

Bern Shen was recently the head of the Institute for the Future's health practice and is currently the Director of Strategic Research Initiatives in Intel's Digital Health group, a Clinical Assistant Professor at UCSF, and Board Chair-elect of The Health Trust, a nonprofit foundation working broadly to improve health in Silicon Valley.

The changing demographic and disease profiles in the US and abroad raise challenging questions about the future of health and healthcare. Overlaying shifts in technology, healthcare financing and culture makes the landscape complex, indeed. Successful design, deployment and evaluation of technology depend on understanding this complex context.

Dr. Shen will draw on his background in technology forecasting, clinical practice and health policy to set the stage for our discussion of elders' information needs and the use of technology to meet those needs. Citing examples from some leading edge clinical and technology groups, he will sketch some of the major trends and "wild cards" that may affect the health and information needs of elders, and their implications for the intersection of health, technology and business in the next decade.

Susannah Fox – Seniors and the Internet

Susannah Fox is an Associate Director at the Pew Internet & American Life Project, a research organization funded by the Pew Charitable Trusts to examine the social impact of the Internet. Ms. Fox has focused on issues related to health and health care, privacy and security, and the differences among generations of Americans in regards to the Internet. She is the former editor of the web site for U.S. News & World Report.

Despite a 10-point increase in the percentage of adults who go online over the past three years, the percentage of those who have never used the Internet and do not live in an Internet-connected household has not changed. The 22% of American adults who are "truly disconnected" are overwhelmingly over age 70 and have less than a high school education. The recent growth in the percentage of older Internet users comes from current users "aging into" the older demographic and holding on to their Internet connections. Indeed, the highly-wired Baby Boomers will transform the senior demographic in the coming years, but off-line seniors will remain in the U.S. population. There is also a divide when it comes to online activities.

Internet users ages 12 to 28 years old are the most likely to embrace the online applications that enable communicative, creative, and social uses (instant messages, online games, blogs). Internet users ages 29 to 69 years old are more likely than Internet users in other age groups to engage in online activities that require some capital: travel reservations and online banking. Internet users age 70 and older are as likely as their younger peers to use email, look for health information, and search for religious information online, but in general, older Internet users are less likely to have a broadband connection at home and less likely to have tried a wide range of online activities.

Ms. Fox, in presenting these trends in Internet adoption and usage, will focus on the special case of older Americans – their attitudes, patterns of use, and implications for the future.

Sara Czaja – The Implications of Aging for E-Health: Trust and Usability Considerations

Sara J. Czaja is a Professor in the Departments of Psychiatry and Behavioral Sciences, and Industrial Engineering at the University of Miami. She is also the Co-Director of the Center on Aging at the University of Miami and the Director of the Center on Research and Education for Aging and Technology Enhancement (CREATE), funded by the National Institute on Aging and involving collaboration with the Georgia Institute of Technology and Florida State University. CREATE focuses on making technology more accessible, useful, and usable for older adult populations. Dr. Czaja recently co-authored a book with other members of the CREATE team concerning the design of technology for older adult populations.

Consumers are increasingly using the Internet to search for health information. One concern relates to the ability of people who are "non medical specialists" to integrate and interpret the wealth of information that is available especially given the increasing number of information sources.

Dr. Czaja will present data from a series of studies examining the ability of older adults to find and interpret Internet-based health information. The initial study examined the relationship between cognition and Internet search performance among a sample of 50 adults ranging in age from 18-85 years. Participants completed a cognitive battery and seven health information seeking problems. They were also given a structured interview that assessed knowledge related to the Internet. The results indicate that both knowledge and cognitive abilities are important predictors of performance. The second study examined the ability of older adults to find and interpret Internet-based health information to answer queries related to health insurance (Medicare Part D). The

sample included 60 adults ranging in age from 50-80 years with varying amounts of Internet experience. Data from this study provide information on the ability of the participants to make "sense" of the information and answer the queries. Dr. Czaja will discuss the type of performance difficulties encountered. She will present information on perceptions of usability and trust in Internet health information and she will discuss the implications from both studies for training and Internet design.

David R. Kaufman – Promoting Health Information Seeking Competencies via CBOs

David Kaufman is an Associate Research Scientist in the Departments of Biomedical Informatics and Psychiatry at Columbia University. His primary research interest is human computer interaction in the context of health information technologies, especially as it relates to older adults and digital divide populations. He has applied video-analytic cognitive science methods to the study of the productive use of technology by clinicians and patients. Trained as an educational psychologist and cognitive scientist, he has conducted several usability evaluation and training studies for the Informatics for Diabetes Education and Telemedicine (IDEATel) project.

Online access to health information can empower patients and consumers to take a more active role in the health care process. Empowerment can result in better-informed decision making, increased patient adherence and better medical outcomes. However, significant challenges exist in reaching digital divide populations who are likely to be older, less educated, and novice computer users. Although older adults are enthusiastic about searching for health information on the net, studies have shown that they are less successful in finding information as compared to younger adults. In addition, seniors often have more difficulty acquiring computer skills than younger people.

Dr. Kaufman will present the results to date of a collaboration among the Department of Biomedical Informatics at Columbia University, the New York Academy of Medicine, and three community-based organizations (CBOs) in East Harlem in developing a community-based program to foster the health information-seeking competencies of disadvantaged inner-city residents who participate in the CBOs' social services programs. The research aims to develop a robust and sustainable "train-the-trainer" model program and to characterize changes in health information-seeking behavior by program participants as a result of the training. The program offers train-the-trainer classes, which are taught by a consumer health librarian and are targeted at CBO employees and volunteers; and consumer health classes for participants. There are three interdependent objectives

that guide this research: 1) develop and refine pedagogical materials; 2) refine methods of evaluation, especially for characterizing changes in health information-seeking competencies; and 3) develop strategies for facilitating implementation in CBOs. Although numerous challenges remain, our experience to date with seniors has strengthened our belief that community-based organizations are excellent places for teaching seniors to access health information on the web.

Related publications by panelists

Shen, B. Ecologies, outreach, and the evolution of medical libraries. In: Peay, W. and Rockoff, M., eds., *Symposium on Community-Based Health Information Outreach*, National Library of Medicine, Bethesda, Maryland, December 2 & 3, 2004. Special Supplement to the *JMLA*, 93(4) 2005.

Fox, S. Digital Divisions: There are clear differences among those with broadband connections, dial-up connections, and no connections at all to the Internet. *Pew Internet & American Life Project*, October 5, 2005.

Fox, S. Older Americans and the Internet. *Pew Internet & American Life Project*, March 28, 2004.

Czaja, S.J. & Lee, C.C. The potential influence of the Internet on the transition to older adulthood. In: *New dynamics in old age: individual, environmental and societal perspectives*. Wahl, H.-W., Tesch-Roemer, C. & Hoff, A., eds. In press.

Czaja, S.J., Charness, N., Fisk, A.D., *et al.* Factors predicting the use of technology: findings from the Center on Research and Aging and Technology Enhancement (CREATE). *Psychology and Aging*. In press.

Kaufman, D.R., Patel, V.L., Hilliman, C.A., *et al.* Usability in the real world: assessing medical information technologies in patients' homes. *J. Biomedical Informatics*, 36, 45-60. 2003.

Kaufman, D.R. & Rockoff, M.L. Promoting online health information-seeking in seniors: a community-based organizations approach. *Generations*. In press.

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