

# Information, Interaction and Innovation in Consumer Health: New Directions at the Intersection of Information Science and Informatics

*Interaction Track ~ Sponsored by SIG-HEALTH*

Tiffany Veinot  
University of Michigan School of Information  
4429 North Quad, 105 S. State Street  
Ann Arbor, MI 48109-1285  
tveinot@umich.edu

Maria Souden  
University College Dublin School of Information  
& Library Studies  
Belfield, Dublin 4, Ireland  
maria.souden@ucd.ie

## ABSTRACT

Longstanding approaches to health and health care are failing us: costs have skyrocketed while care quality remains highly uneven; the majority of health care in North America takes place in homes and communities rather than hospitals and doctor's offices; and institutionalized health care often does little to support people psychosocially or prevent people from becoming ill in the first place. Enthusiasm for the potential of consumer participation in health and health care has found advocates among health systems and insurers keen to reduce costs and patient organizations agitating for improved recognition and care. Alongside these trends, we find an increased focus on consumer health in the disciplines of information science and informatics. Health information science studies examine information behavior, information policy, terminology and information retrieval systems. Health informaticians focus on the design and evaluation of consumer-facing technologies such as personal health records and health behavior tracking systems. Scholars in both fields pursue research concerning social media, including online patient communities. However, despite the growing momentum of scholarly activity in both fields, as well as their topical overlap, the fields remain largely separate, with differing research traditions and scholarly communities. In this panel, we find synergy and common ground between the two fields through an exploration of the conference themes of information, interaction and innovation. In a lightning talk format, eight panelists representing diverse research areas will share their perspectives upon key insights that each field can bring to the other. Building on the arguments presented, panelists and the audience will reflect on the state of consumer health research, and brainstorm regarding future scholarly directions that will leverage the strengths of both fields.

## KEYWORDS

Consumer health, information science, informatics

*ASIST 2012*, October 28-31, 2012, Baltimore, MD, USA.

Copyright 2012 Tiffany Veinot and Maria Souden

## INTRODUCTION

It is increasingly understood that longstanding approaches to health and health care are failing us. Since the 1970s, health care spending has outpaced economic growth in most OECD countries, with health spending as a proportion of GDP reaching a high of 17.4% in the United States (Organisation for Economic Co-operation and Development (OECD), 2012). At the same time, care quality is uneven in many countries (e.g., Canadian Health Services Research Foundation, 2010; Sutherland & Coyle, 2009). A mounting critique points to the mismatch between health care systems historically designed around acute care needs and the growing demographic shift towards a chronic disease pattern (Anderson & Horvath, 2004). Hence, advocates tout the need to transform the current "sick care" system into a "health care" system emphasizing preventative care and health promotion (e.g., Sebelius, 2010). Although psychosocial needs are an important determinant of health, the health care system is poorly equipped to address them (Robert Wood Johnson Foundation, 2011). The formal health care system also provides only a small amount of the care that is provided; for example, the economic value of care provided to elderly adults in the US is more than twice annual expenditures on home care and nursing home care (National Alliance for Caregiving, 2009).

In the face of these enormous gaps and challenges, there is growing enthusiasm for expanded consumer participation in health and health care. This enthusiasm emanates from diverse groups with varied aims. Advocates suggest that patients can help to address persistent problems with safety in health care (Davis, Jacklin, Sevdalis, & Vincent, 2007). Patient "self-management" programs are funded by the governments of various American states, as well as the governments of the UK and Australia (e.g., Jordan, Briggs, Brand, & Osborne, 2008; Veinot, 2010). In efforts to reduce health care costs, health insurers and employers are increasingly designing programs that provide incentives for healthy behaviors such as exercise (e.g., Volpp, Asch, Galvin, & Loewenstein, 2011). And health social

movements advocate for increased recognition and voice in health care (Brown, 2012).

### **NEW RESEARCH FRONTIERS**

Consumer health information and technologies are seen to be essential to such expanded roles for consumers and patients. In part, expanded information availability may correct traditional information asymmetries between physicians and their patients. This understanding was reflected in the initial efforts of the consumer health information movement to develop information services in many libraries and non-profit organizations (Huber & Gillaspay, 2011). Today, more than half of online health information seekers have used information obtained from the Internet to ask their doctor new questions, or to seek a second opinion (Fox, 2011). Furthermore, the convergence of digital forms of information, social media and mobile computing has made new types of consumer health information technologies possible. For example, sites like PatientsLikeMe may facilitate new forms of biomedical research drawing from patient-generated content (e.g., Wicks, Vaughan, Massagli, & Heywood, 2011). The growing ubiquity of smartphones has also enabled the creation of mobile consumer health applications that commonly incorporate features such as reminders and personal tracking (e.g., Estrin & Sim, 2010). New modes of information organization, such as social tagging, are also changing health information acquisition online (e.g., Smith & Wicks, 2008).

In addition to a growing focus on consumer health, information science and informatics have many common objects of study. Yet, the fields remain largely separate, rooted in differing research traditions and speaking to distinct scholarly communities. More fundamentally, their approaches to information problems differ. Health informatics, with its roots in health sciences, tends to focus on changing people: designing interventions and evaluating their efficacy. As the American Medical Informatics Association (AMIA) describes, biomedical informatics is "...the interdisciplinary, scientific field that studies and pursues the effective uses of biomedical data, information, and knowledge for scientific inquiry, problem solving and decision making, motivated by efforts to improve human health." (American Medical Informatics Association, 2012) Hence, health informaticians focus on the design and evaluation of consumer-facing technologies, such as personal health records, health behavior tracking systems and design of patient communities.

In contrast, information science has been more focused on observing people and trying to develop systems and services that will accommodate observed characteristics. This orientation is evident in definitions of the field that highlight information science's concerns with enabling people to become better informed (Buckland, 2012), and its focus on recorded knowledge and on techniques for

facilitating access to, and use of, recorded knowledge (Saracevic, 1999). Accordingly, health information science studies examine information behavior, social informatics, information policy, terminology and information retrieval systems from a more facilitative perspective.

### **CONVERGENCE AND COMMON GROUND**

The ASIST Annual Meeting offers an ideal ground to bring health information science and health informatics together, and, in keeping with the conference's 75<sup>th</sup> anniversary theme, to construct our common present while co-creating a more powerful future. From a platform of common interest and concerns, this panel will bring together diverse perspectives of consumer health researchers working in both fields. The panelists have been asked to comment on the state of information, innovation and interaction research within their respective areas of study in order to address the following questions:

- What are the areas of theoretical, methodological and topical convergence and divergence between health information science and health informatics?
- What opportunities are there for mutual collaboration?
- What is the potential for a broader synthesis of the two fields that will more robustly inform research questions and approaches in the future?

The eight panelists will present their perspectives on key insights that each field can bring to the other in the form of "lightning talk" presentations of seven minutes or less. The lightning talk format forces speakers to make only their strongest points, focusing on the essence of their message and minimizing the chances of "wandering into the empty rhetoric" (Berkun, 2010) that can arguably establish barriers rather than facilitating convergence. This hour of lightning talk presentations is intended to focus the audience's attention on core research issues in consumer health information and stimulate a provocative discussion of the potential synergies of the two fields going forward. To aid in audience reflection, panelists will present in a sequence based on their levels of engagement in each of the two fields, ranging from health informatics-identified to information science-identified scholars, and the spaces in between.

To promote interactivity and scaffold follow-up discussion, session participants will be asked to record their thoughts on the three questions above as the panelists present. Following the lightning talks, small groups of 8-10 audience members will be formed in order to compare notes and develop a consensus from their group on the most viable and inspired opportunities for collaboration across the two fields. The session will end with the sharing of group summaries and final thoughts. Individual and group contributions will be collected by the panel organizers and used as a springboard for organizing the future development of an academic piece that articulates the synthesis of information science and informatics with regards to

consumer health and proposes a potential research agenda that leverages the strengths of the two fields.

## PANELISTS AND THEIR PERSPECTIVES

**Maria Souden, MSI, PhD** (moderator), is a *Postdoctoral Research Fellow at University College Dublin School of Information and Library Studies*. Souden's research looks at the roles and meanings of information in dealing with chronic illness from a patient-centered perspective and examines how the patient experience of information is shaped by the healthcare context. Souden, an experienced presenter, moderator and small-group facilitator, will provide an overview of the conceptual framework for the panel and facilitate the follow-up discussion for the session.

**Charles Friedman, PhD** is *director of the new health informatics program at the University of Michigan, having returned to academia after federal service as Deputy Director and Chief Scientific Officer in the Office of the National Coordinator for Health IT*. Friedman will take the perspective that a bottom-up revolution is occurring in the application of information technology to health. This revolution is most apparent in the development of consumer-facing applications that add value to data that consumers themselves generate as well as to institutionally-generated data that are increasingly available in electronic form. There is tremendous energy in this space, which has been dubbed "Health 2.0", as well as tremendous opportunity. However, to empower this revolution, a new type of professional is needed, who is knowledgeable in technology, policy and health but also entrepreneurial and steeped in a culture of agile application development.

**Catherine Arnott Smith, AMLS, MA, MS, PhD**, is *Associate Professor at the School of Library and Information Studies and Faculty in Residence in the Living Environments Laboratory, Wisconsin Institutes of Discovery, University of Wisconsin-Madison*. Smith proposes an analogy between the history of medicine and medical informatics. Each is a field originally dominated by clinicians; each has been invaded and had its trajectory and its community dialogue substantially altered through an influx of nonclinical participants. Each field has had a particular traditional orientation towards laypersons, or "consumers", which has had to change as researchers and their perspectives have changed. There are lessons here for library and information science, which has had its own interdisciplinary shifts and schisms to contend with. Medical informatics researchers working with problems of consumer health need to see library and information scientists as potential partners; and vice versa.

**Tiffany Veinot, MLS, PhD**, is *Assistant Professor of Information and of Health Behavior and Health Education at the University of Michigan*. She is also a founding faculty

*member of the University of Michigan's new health informatics master's degree program*. Veinot will argue that information science offers health informatics useful insights concerning information policy and institutions. Drawing from research with marginalized communities and families, Veinot will argue that not all consumer health information problems are best addressed through technological systems. Some information problems may, for example, be better-addressed through design of: policies, incentives, workflows, routines, social networks, locally-relevant content, face-to-face interactions or other forms of intervention. Or, in some situations, interventions that incorporate technologies and some of these other elements may be optimal. Furthermore, she argues that information science could be enriched by the health informatics field's strengths in evaluation methodologies — particularly those that connect health information and technologies to health outcomes.

**Yunan Chen, PhD** is *Assistant Professor in the Department of Informatics at the Donald Bren School of Information and Computer Sciences, and the Institute for Clinical and Translational Science at the University of California Irvine*. Chen will argue that the design of health informatics applications will benefit significantly from the theories and practices in information science. Health practices are essentially information-driven, relying on the effective use and coordination of health related information among groups of heterogeneous participants. Health information must be articulated, coordinated, reconciled and integrated in order to support health management practices. Failure to address this critical aspect may lead to flaws and inefficiencies in developing health informatics applications. Chen will introduce issues of information integration, communication and coordination in maintaining illness trajectories, and discuss why designing technologies requires sufficient understanding of information behaviors and models.

**Barbara Wildemuth, MLS, MEd, PhD.**, is *Professor and Associate Dean for Academic Affairs in the School of Information and Library Science at the University of North Carolina at Chapel Hill*. Wildemuth will discuss the design of personal health records as a challenge to which a variety of fields can contribute, including both information science and health informatics. Collaborators from the health disciplines contribute the necessary medical expertise. Because personal health records are both consumer-facing and provider-facing, with the healthcare consumer being responsible for their accuracy and use, principles used to design electronic medical records will be useful as a starting point but are not likely to be completely valid for the development of such a consumer-oriented tool. Information science's emphasis on user interests and user information needs can provide a balancing influence in this design arena.

**Lynne Howarth, PhD**, is Professor and Associate Dean for Research at the Faculty of Information at the University of Toronto. Howarth is conducting a SSHRC-funded exploratory study that situates cognitive science concepts of representation and memory within the information science (IS) framework of sense-making and recall strategies. The research examines how individuals with early stage or mild Alzheimer/Dementia (AD) use surrogates representing people, places, things, or events retold in participant interviews for recalling life stories. How and how effectively are information artifacts, such as music, photographs, tactile objects, etc., used as memory cues for (re)constructing personal narratives? Howarth will argue that IS approaches and tools can positively influence the current standard of care and clinical practice for AD.

**Ellen Rubenstein, MLS, PhD** is an Assistant Professor at the School of Library and Information Studies at the University of Oklahoma. Rubenstein will argue that social support and informal patient communication are integral aspects of acquiring health information from both information behavior and informatics perspectives. Information behavior research has exhibited the importance of informal information sharing in everyday life, and these ideas can be extended to health informatics platforms. For online communities, design that takes into account the integration of social support and social relationships among patients in collaborative information sharing environments can benefit personal health and overall wellbeing.

## REFERENCES

- American Medical Informatics Association. (2012). What is informatics? Retrieved April 29, 2012, from <http://www.amia.org/>
- Anderson, G., & Horvath, J. (2004). The Growing Burden of Chronic Disease in America. *Public Health Reports*, 119, 263-270.
- Berkun, S. (2010). The end of boring presentations. Retrieved April 30, 2012, from <http://www.forbes.com/2010/01/14/presentations-pecha-kucha-technology-breakthroughs-oreilly.html>
- Brown, P. (2012). *Contested illnesses: citizens, science, and health social movements*. Berkeley: UC Press.
- Buckland, M. (2012). What kind of science can information science be? *Journal of the American Society for Information Science and Technology*, 63(1), 1-7.
- Canadian Health Services Research Foundation. (2010). Quality of Healthcare in Canada. Retrieved April 29, 2012, from <http://www.chsrf.ca/>.
- Davis, R. E., Jacklin, R., Sevdalis, N., & Vincent, C. A. (2007). Patient involvement in patient safety: what factors influence patient participation and engagement? *Health Expectations*, 10(3), 259-267.
- Estrin, D., & Sim, I. (2010). Open mHealth Architecture: An Engine for Health Care Innovation. *Science*, 330(6005), 759-760.
- Fox, S. (2011). The Social Life of Health Information, 2011 Retrieved April 30, 2012, from <http://pewinternet.org/Reports/2011/Social-Life-of-Health-Info.aspx>
- Huber, J. T., & Gillaspay, M. L. (2011). Knowledge/Power Transforming the Social Landscape: The Case of the Consumer Health Information Movement. *The Library Quarterly*, 81(4), 405-430.
- Jordan, J. E., Briggs, A. M., Brand, C. A., & Osborne, R. H. (2008). Enhancing patient engagement in chronic disease self-management support initiatives in Australia: the need for an integrated approach. *Medical Journal of Australia*, 189(10), S9-S13.
- National Alliance for Caregiving. (2009). The Evercare Survey of The Economic Downturn and its Impact on Family Caregiving Retrieved April 29, 2012, from [http://www.caregiving.org/data/EVC\\_Caregivers\\_Economy\\_Report\\_FINAL\\_4-28-09.pdf](http://www.caregiving.org/data/EVC_Caregivers_Economy_Report_FINAL_4-28-09.pdf)
- Organisation for Economic Co-operation and Development (OECD). (2012). OECD Health Data 2011. Paris, France.
- Robert Wood Johnson Foundation. (2011). Health care's blind side: The overlooked connection between social needs and good health Retrieved April 29, 2012, from <http://www.rwjf.org/vulnerablepopulations/>
- Saracevic, T. (1999). Information science. *JASIST*, 50(12), 1051-1063.
- Sebelius, K. (2010). From Sick Care to Health Care Retrieved April 29, 2012, from <http://www.hhs.gov/secretary/about/opeds/charleston.html>
- Smith, C. A., & Wicks, P. (2008). *PatientsLikeMe: Consumer Health Vocabulary as a Folksonomy*. Paper presented at the AMIA Annu Symp Proc.
- Sutherland, K., & Coyle, N. (2009). Quality of healthcare in England, Scotland, Wales and Northern Ireland: an intra-UK chartbook Retrieved April 29, 2012, from <http://www.health.org.uk/>.
- Veinot, T. C. (2010). Power to the Patient? A Critical Examination of Patient Empowerment Discourses. In R. M. Harris, C. N. Wathen & S. Wyatt (Eds.), *Configuring Health Consumers: Health Work and the Imperative of Personal Responsibility* (pp. 30-41). New York: Palgrave.
- Volpp, K. G., Asch, D. A., Galvin, R., & Loewenstein, G. (2011). Redesigning Employee Health Incentives — Lessons from Behavioral Economics. *NEJM*, 365(5), 388-390.
- Wicks, P., Vaughan, T. E., Massagli, M. P., & Heywood, J. (2011). Accelerated clinical discovery using self-reported patient data collected online and a patient-matching algorithm. *Nature Biotechnology*, 29(5), 411-414.