iConference 2018 Workshop Proposal – Health Informatics

Title: *Towards Meaningful Engagement: Challenges and Opportunities to Facilitating Information Flow and Use to Support Health and Wellness*

Organizers:
Charles Senteio, PhD, MSW, MBA
Assistant Professor, Rutgers University School of Communication & Information
Department of Library and Information Science, New Brunswick, NJ USA

Christine T. Wolf, JD, PhD
Research Staff Member, IBM Research
Almaden Research Center, San Jose, CA, USA

Abstract:
Despite rapid advances in health information-gathering technologies barriers persist between patients or health consumers and health care providers in not only *sharing* health information, but also in facilitating *valuable engagement and use* of health information. We propose a half-day workshop at iConference 2018 aimed at bringing together a diverse range of participants from around the world to identify barriers to, and opportunities for, information sharing to support health and wellness. We focus on three workshop themes (health informatics; data analytics; and user experience design) to discuss the ongoing challenges in this area. We are interested in using this workshop to provide an arena for discussions about how to increase patient engagement through information use, given the rapid advances in health technologies, the diverse stakeholders implicated in the health context, and the ongoing challenges of designing for engagement.

Description:

1. Purpose and Intended Audience
The proposed workshop aims to bring together a diverse range of global participants to identify barriers to, and opportunities for, information sharing to support health and wellness. In particular, we are interested in examining the divide between patients or health consumers and health care providers in not only *sharing* health information, but also in facilitating *valuable engagement and use* of health information. Our interest in fostering engagement and use is motivated by its consequential effects: patient engagement leads to better health outcomes, regardless of the numerous payer policies of health systems around the world. For two decades, patient engagement has been recognized as a critical component in improving health outcomes [1]. Patient engagement presents a complex design problem: beyond simply providing health information, the design and development of health tools and services must also consider how to facilitate flow between patients and providers, empowering patients to be "copilots" in their own care [2].

While technological advances expand our ability to collect health information – for example, through electronic health record systems (EHRs), as well as novel consumer devices like wearables and other personal tracking technologies – providers and patients still report difficulties in engaging with *each other* around these information sources [3-7]. Multiple sources of tension contribute to these barriers – for example, issues within the healthcare system (e.g., disparate systems for primary and specialty care providers), as well as between providers and patients during the clinical encounter (i.e., socio-cultural factors and lack of access to patient-centric information during the clinical visit) [8]. Further, a growing

digital divide excludes many – such as elders, minority groups, and other individuals with limited health technology literacy – from participating in the possible benefits envisioned by health technology advances [9, 10].

Given these challenges, we are interested in using this workshop to provide an arena for discussions about how we can work to increase patient engagement through information use, given the rapid advances in health technologies, the diverse stakeholders implicated in the health context, and the ongoing challenges of designing for engagement.

Towards this goal, the proposed workshop is organized around three themes:
1) **Clinical Care Delivery** - identifying facilitators of information flow and information needs at the point of care with a particular emphasis on emerging technology;
2) **Data Analytics** – considering questions that arise from incorporating information gleaned from multiple and disparate data streams (e.g., technical feasibility; utility and quality of data sources; limitations of partial and incomplete data; risk of algorithmic bias);
3) **User Experience Design** – considering the unique design challenges of increasing meaningful engagement and information flow in the health context, given the complexity of health and wellness information (e.g., challenges of health literacy and numeracy) as well as designing user experience given the considerable diversity of users (e.g., providers, patients, caregivers).

1.1. Intended Audience

The iSchools' interdisciplinary and international community of scholars makes the iConference an ideal place to discuss the challenges and opportunities of enhancing information flow to support health and wellness. The proposed workshop aims to convene a group of individuals with a diverse range of perspectives. We will attract workshop participation from academic and industry researchers, and information professionals.

2. Proposed Format

2.1. Schedule

0 - 15min	Welcome and Introductions
15min – 1hr 30min	Breakout based on Themes (facilitators assigned prior based on papers submitted and vetted by workshop organizers): 1. Clinical Care Delivery 2. Data Analytics 3. User Experience Design
1hr 30min – 2hr	Group Discussion – Challenges and Opportunities • Report out from each breakout
2hr – 2hr 15min	**Break**
2hr 15min – 3hr 30min	Interdisciplinary Discussions 1. Clinical Care Delivery – Data Analytics 2. Clinical Care Delivery – User Experience Design 3. Data Analytics – User Experience Design
3hr 30min – 4hr	Group Discussion – Challenges and Opportunities • Report out from each breakout

	• Potential Collaboration Beyond iConference
4hr – 4hr 15min	Wrap up and Conclusion

2.2. Call for Position Papers

We aim to conduct a workshop that maximizes idea exchange. All interested researchers, graduate students, clinicians, and information science professionals are invited to submit a position paper (1200 word limit) in which they describe the topic they propose to discuss and how it relates to one or more of the three workshop themes. Interested individuals should submit their proposal to HealthInformatics.iConf2018@senteio.com by January 21, 2017 11:59pm GMT. Position papers should clearly indicate applicability to *one or more of the three* workshop themes and should include the following three sections:

1) Topic/Project: indicate if the proposal describes a research project or practitioner experience. If proposal is part of a research project describe the topic and context, include methods and stage of the project. If the proposal describes practitioner experience, discuss relevancy to the workshop in context of the work.
2) Tie to Themes: state how the proposal relates to one or more of the workshop themes
3) Goals: state what you hope to get out of the workshop, indicate if there are other themes you would like to interface with in group breakouts.

Prior to the workshop, the organizers will use submitted position papers to organize small groups and identify group leads for discussions on a number of topics (see **List of Proposed Topics**) related to information flow for consumers (patients/caregivers) and providers.

3. Goals or Outcomes

The workshop will curate new ideas within the information science community concerning improvements in information flow and engagement for health and wellness. We hope to form collaborations during the half-day workshop which result in new research teams among workshop attendees. Organizers will encourage collaborations through facilitation during the workshop; following the workshop, we will distribute discussion notes and attendee contact information.

4. Relevance to the iConference

The iConference features various topics surrounding the relationships among information, people, and technology. We believe this workshop will help advance the field of health informatics by spurring intense discussions deliberating the confluence of issues associated with enhancing information flows and meaningful engagement associated with health and wellness.

5. Duration

The workshop will be a half-day event

6. Expected/Preferred Number of Participants

We expect approximately 30 participants. We will limit participation to 45 in order to ensure a cohesive group with opportunities for interactions.

List of proposed topics (we would like to include this list in proposal call, if permitted given word limits)
Topics include, but are not limited to the following:

- **Health Informatics**
  - *Information Flows*
    - Emerging technology to facilitate health information flow between patients/caregivers and providers
    - Data needs of care coordination (e.g. care transitions, community-based health/wellness resources)
    - Financial incentives for health information sharing and integration
  - *Vulnerable and Underserved Populations*
    - Vulnerable populations (e.g., elderly, minorities, disabled, immigrants, refugees) and personal health technology
    - Factors presenting barriers to care and expanding access for the underserved Enhancing health informatics tools to address disparities in access to primary and specialty care
  - *Health Information Seeking Behavior*
    - Applicability of relevant information behavior theories and/or conceptual lenses in addressing barriers of health information flow and engagement
    - Role of different professions in health information behavior (e.g., librarians, allied health, etc.)
    - Role of different community institutions and services in health information behavior (e.g., government programs, libraries)
    - Role of library expertise and specialties in health information behavior (e.g., public, academic, and medical libraries and librarians)

- **Data Analytics**
  - *Data Access*
    - Issues of data access, technical interoperability, and data quality
    - Data types and the scope of possible insights (e.g., streaming versus historical data; acute versus chronic health encounters; granularity of data and ability to provide individual/group/population level insights)
  - *Automation and Personalization*
    - Role of artificial intelligence, algorithmic, and other automated outputs in clinical care
    - Expertise and situated decision-making in clinical care
  - *Practice Transformation*
    - Integration and transformation of existing workflows and routines with health analytics
    - Impacts on occupational authority, expertise, and control in the clinical encounter (e.g., possible challenges and consequences of "patients as copilots" as well as "algorithmic management")
  - *Privacy and Security*
    - Ensuring privacy and security compliance with increased information flow
    - Identifying and measuring potential risk and harm from integrated health data systems

- **User Experience Design**
    - *Cognitive Load*
        - Designing with diversity in health and data literacy in mind
        - Novel visualization, display, and interaction design strategies to decrease cognitive load
    - *Continuity and Personal Information Management*
        - Designing for multi-system, multi-app health IT ecosystems
        - Self-tracking across platforms
    - *Supporting Health Care Ecosystems*
        - Mapping diverse stakeholder interests in the design of health information technologies and services (e.g., patients, providers, caregivers)
        - Designing for user constellations (i.e., complex user arrangements that accommodate different stakeholders and different interests)

References

1. Carman, K.L., et al., *Patient And Family Engagement: A Framework For Understanding The Elements And Developing Interventions And Policies.* Health Affairs, 2013. **32**(2): p. 223-231.
2. Tang, P.C. and D. Lansky, *The Missing Link: Bridging The Patient–Provider Health Information Gap.* Health Affairs, 2005. **24**(5): p. 1290-1295.
3. Bietz, M.J., et al., *Creating Meaning in a World of Quantified Selves.* IEEE Pervasive Computing, 2016. **15**(2): p. 82-85.
4. Kreitmair, K.V., M.K. Cho, and D.C. Magnus, *Consent and engagement, security, and authentic living using wearable and mobile health technology.* Nat Biotech, 2017. **35**(7): p. 617-620.
5. Piwek, L., et al., *The Rise of Consumer Health Wearables: Promises and Barriers.* PLoS Medicine, 2016. **13**(2): p. e1001953.
6. Hassan, L., et al., *Tea, talk and technology: patient and public involvement to improve connected health 'wearables' research in dementia.* Research Involvement and Engagement, 2017. **3**(1): p. 12.
7. Chiauzzi, E., C. Rodarte, and P. DasMahapatra, *Patient-centered activity monitoring in the self-management of chronic health conditions.* BMC Med, 2015. **13**(77).
8. Wong, E.L.Y., et al., *Views and Experience on Patient Engagement in Healthcare Professionals and Patients—How Are They Different?* Open Journal of Nursing, 2017. **07**(06): p. 615-629.
9. Lyles, C.R., et al., *mHealth and Health Information Technology Tools for Diverse Patients with Diabetes.* Journal of diabetes research, 2017. **2017**: p. 1704917.
10. Kelley, M.S., D. Su, and D.H. Britigan, *Disparities in Health Information Access: Results of a County-Wide Survey and Implications for Health Communication.* Health Communication, 2016. **31**(5): p. 575-582.
11. Senteio, C.R., et al., *The Impact of the EHR on the Collection and Retrieval of Psychosocial Information in Outpatient Diabetes Care*. 2017: Manuscript Submitted for Publication.
12. Bejan, C.A., et al., *Mining 100 million notes to find homelessness and adverse childhood experiences: 2 case studies of rare and severe social determinants of health in electronic health records.* Journal of the American Medical Informatics Association, 2017.
13. Jeong Yi, Y., *Consumer Health Information Behavior in Public Libraries: A Qualitative Study.* The Library Quarterly, 2015. **85**(1): p. 45-63.
14. Pine, K., C.T. Wolf, and M. Mazmanian, *The Work of Reuse: Birth Certificate Data and Healthcare Accountability Measurements*, in *iConference 2016*, i. Proceedings, Editor. 2016.
15. Swan, M., *Health 2050: The Realization of Personalized Medicine through Crowdsourcing, the Quantified Self, and the Participatory Biocitizen.* Journal of Personalized Medicine, 2012. **2**(3): p. 93.
16. Lee, M.K., et al., *Working with Machines: The Impact of Algorithmic and Data-Driven Management on Human Workers*, in *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*. 2015, ACM: Seoul, Republic of Korea. p. 1603-1612.
17. Hajian, S., F. Bonchi, and C. Castillo, *Algorithmic Bias: From Discrimination Discovery to Fairness-aware Data Mining*, in *Proceedings of the 22nd ACM SIGKDD International Conference on Knowledge Discovery and Data Mining*. 2016, ACM: San Francisco, California, USA. p. 2125-2126.
18. Chen, Y., V. Ngo, and S.Y. Park, *Caring for caregivers: designing for integrality*, in *Proceedings of the 2013 conference on Computer supported cooperative work*. 2013, ACM: San Antonio, Texas, USA. p. 91-102.
19. Wolf, C.T. and T.C. Veinot, *Struggling for space and finding my place: An interactionist perspective on everyday use of biomedical information.* Journal of the Association for Information Science and Technology, 2015. **66**(2): p. 282-296.

20.   Kaziunas, E., et al., *Transition and Reflection in the Use of Health Information: The Case of Pediatric Bone Marrow Transplant Caregivers*, in *Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing*. 2015, ACM: Vancouver, BC, Canada. p. 1763-1774.
21.   Ancker, J.S. and D. Kaufman, *Rethinking Health Numeracy: A Multidisciplinary Literature Review.* Journal of the American Medical Informatics Association, 2007. **14**(6): p. 713-721.