

Symposium Highlights and Synopses of the Scientific Program

The Sixth Annual Mid-Atlantic Healthcare Informatics Symposium

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Summary

As the bar to actively participate in one's own health is consistently lowered through technology, patients are helping to evolve traditional workflows to make data more accessible at the point of care. This growing trend of patient engagement and personalized medicine was the focus of the 2013 Mid-Atlantic Healthcare Informatics Symposium in Philadelphia, PA on April 26, 2013. The conference, presented annually by the Center for Biomedical Informatics (CBMi) at The Children's Hospital of Philadelphia, featured plenary sessions, panel discussions, and paper presentations on a range of topics, including patient engagement and personalized medicine; using data and analytics to optimize patient care; nursing informatics; and the future of biomedical informatics.

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1. Introduction

Healthcare informatics continues to evolve as more organizations rely on technology to comply with changing regulations, improve patient care, and provide a higher level of support for health care providers. Patient data is more accessible than ever. As the bar to actively participate in one's own health is consistently lowered through technology, patients are helping to evolve traditional workflows to make data more accessible at the point of care [1–7]. This growing trend of patient engagement and personalized medicine was the focus of the 2013 Mid-Atlantic Healthcare Informatics Symposium in Philadelphia, PA on April 26, 2013. The conference, presented annually by the Center for Biomedical Informatics (CBMi) at The Children's Hospital of Philadelphia, featured plenary sessions, panel discussions, and paper presentations on a range of topics including: patient engagement and personalized medicine; using data and analytics to optimize patient care; nursing informatics; and the future of informatics. Links to videos from the Symposium are provided throughout this article.

2. Background of the Symposium

The Mid-Atlantic Healthcare Informatics Symposium has rapidly grown into a strong, academically focused event, since its inception in 2008. In recent years the Symposium has attracted more than 300 participants from over 65 organizations. Although a majority of the symposium participants come from the Northeast/Mid-Atlantic region, the conference recruits nationally known informatics experts who provide participants with the latest trends within health and biomedical informatics. The goal of the Symposium is to provide participants with a better understanding of informatics, especially as it enhances health through research, innovative technologies, data analytics, policy, and education. Through a combination of keynote presentations, breakout and panel sessions, paper presentations, and poster sessions, participants are introduced to both clinical and translational components of informatics. In addition, it offers an excellent opportunity for networking.

3. Focus on Patient Engagement

On the tenth anniversary of the completion of the human genome project, keynote speaker Dr. Daniel Masys from University of Washington discussed the promise of personal genomics as a “grand challenge of the 21st century for biomedical informatics”. His presentation, “Know Thy Molecular Self: Knowledge Management and Patient Engagement in the Era of Personal Genomes”,

http://www.youtube.com/watch?v=vOW2FyfwbVw&feature=c4-overview-vl&list=PLuyM9kxlfCq7COpOA68JY6msGBm9bJC_o

detailed the “promise” as precision healthcare at the level of the person, direct consumer genomics, but this is not without challenges. He concluded with a three step approach to managing and using personal genomic data for effective personalized care, including:

- Step 1: Get the data into Electronic Health Records (EHRs) in a usable form
- Step 2: Create a people and technology infrastructure to use the data for decision support
- Step 3: Scale the decision support up to enable all providers and all patients and families to benefit, via a public information infrastructure

A Patient Engagement panel followed Dr. Masys' keynote continuing on the theme of personalized medicine. Dr. Alexander Fiks from The Children's Hospital of Philadelphia opened the discussion commenting that “people actively involved in their health and health care tend to have better outcomes and, possibly, lower costs.”

The panel was joined by Regina Holliday, a nationally known patient rights advocate, is a Washington, DC mother, widow, artist, and “data access advocate” who now speaks from the patient perspective about the benefits and the importance of health IT in the engagement of patients and

families in their healthcare, inspired from her own personal loss of her husband and the journey she and her family endured.

As a longtime employee of a toy store, Holliday painted a picture of health IT while “Thinking Outside of the Toy Box.”

http://www.youtube.com/watch?v=9Wptm68b8tk&feature=c4-overview-vl&list=PLuyM9kxlfCq7COpOA68JY6msGBm9bJC_o

Her premise is that everyone’s healthcare needs are unique and do not fit into a “box.”

Sharing many of her experiences, and her many challenges, she asserts healthcare IT can help with the personalization of healthcare, if patients are engaged and given access their own personal health information (“open data”) and a way to voice their personal needs and concerns.

Kaiser Permanente’s Ted Eytan continued the patient engagement discussion

http://www.youtube.com/watch?v=F65B-Kmem18&feature=c4-overview-vl&list=PLuyM9kxlfCq7COpOA68JY6msGBm9bJC_o

and described how Kaiser Permanente connects and actively engages with over 65% of their 9 million members through their patient portal, also now accessible through mobile devices. He described available functionality that includes traditional features such as messaging, access to results, appointment scheduling, etc. but has also branched out into the social media space – where the patients are and where “health and healthcare happens.”

4. The View from the ONC

Judy Murphy, RN, FACMI, FHIMSS, FAAN Deputy National Coordinator for Programs & Policy, Office of the National Coordinator for Health IT Department of Health & Human Services, Washington DC presented “Yesterday, Today and Tomorrow,”

<http://www.youtube.com/watch?v=1NkjkNxsNg>

detailing health informatics accomplishments, key priorities, and the biggest challenges for the future from the ONC perspective. “Patients increasingly expect engagement via IT, as in many other aspects of their lives,” stated Ms. Murphy, and Health IT can be a “hook” to better engage patients in their own care. It isn’t just about the technology, but more about how we practice in a patient-centric way.

She summed up her position as: The **Three A’s Approach** to Consumer Engagement: increase patient’s **Access** to their health information (such as electronic messaging and online access via portals, etc.); Enable them to take **Action** with their information (challenges by the ONC to: develop apps that “mash up” or pull together personal health information improve the patient experience make it more patient-centric); Shift **Attitudes** to support patient-provider partnership with challenges to increase awareness

Finally, she related these priorities to challenges for the future as outlined by the Stages of Meaningful Use. Data capturing and sharing will promote more advanced clinical processes (such as care coordination, patient self management, evidence based medicine, etc.) and ultimately transform healthcare by becoming a continuously learning health system with measurable and improved outcomes, improved population health, and lower costs.

5. The Nursing Perspective on Patient Engagement

University of Wisconsin Madison’s Patricia Flatley Brennan RN, PhD, speaking remotely from the University of Wisconsin Madison, shared “Patient Self-Monitoring and Observations of Daily Living”.

http://www.youtube.com/watch?v=glsy7i7YVWI&feature=c4-overview-vl&list=PLuyM9kxlfCq7COpOA68JY6msGBm9bJC_o

She asserted much of the “care” of patients occurs outside of the healthcare system and engaging patients to make “observations” that occur during these times of daily living (ODLs) are important. Dr. Brennan is national program director of **Project HealthDesign**, a Robert Wood Johnson Foundation national program designed to stimulate the next generation of personal health records (PHRs). She described the program as a “rethinking” of the power and potential of the personal health record using mobile technology and from the perspective of the patient. The Project team focuses on issues such as using a common platform that is independent of the EHR and takes into consideration the needs of and negotiating what is important to the patient. Clinicians then make use of the patient’s ODLs to better dialogue with the patient, to clarify their needs, better understand the patient’s health status at home, correct or make new diagnoses, adjust target-related treatments, make more informed referrals based on increased knowledge of patient’s symptoms, and other factors. A panel discussion followed where Dr. Brennan was joined by Diane Hunbrecht, MSN, Abington Memorial Hospital, American Nursing Informatics Association and the ONC’s Judy Murphy.

6. Using Data and Analytics to Optimize Care

http://www.youtube.com/watch?v=8mid8G2DR_4&list=PLuyM9kxlfCq7COpOA68JY6msGBm9bJC_o

This clinical decision support panel led by Dr. Robert Grundmeier of The Children’s Hospital of Philadelphia addressed the increased reliance on EHR data to inform and improve care practices. Participants included Keith Marsolo, PhD, University of Cincinnati, William Adams, MD, Boston Medical Center, and Richard Wasserman, MD, University of Vermont. All panel participants discussed the challenges and benefits of using data from multiple implementations, formats, and vendors. Each presented a specific case study highlighting their experiences. Dr. Marsolo presented “ImproveCare Now”, an enhanced patient registry linked to the EHR and Dr. Adams gave an overview of the “Home Cell”, a tool for health outcome modeling and evaluation.

The representative presentation was from Richard Wasserman, MD, Professor of Pediatrics at the University of Vermont, Director of the AAP’s pediatric research network PROS (Pediatric Research in Office Settings). With electronic health records now more commonplace in the office setting, Dr. Wasserman saw the need to establish the ePROS network to help generate new knowledge using data from EHRs. However, he discovered the myriad of vendors and data stored in multiple locations – 21 ePROS sites to date in 15 states using 7 different EHR systems with nearly incompatible formats – makes traditional research difficult at best. To assist in these efforts, a dataset is extracted from the practice’s EHR, de-identified, contributing to a HIPAA-limited, single dataset, and stored in an ePROS database for research purposes. Two proof-of-concept studies using this methodology were successful in examining the prevalence of obesity and the prevalence of the use of psychotropic medications in the office setting.

7. Thoughts on The Future of Informatics

The final session of the 6th Annual Mid-Atlantic Healthcare Informatics Symposium postulated the future of informatics

http://www.youtube.com/watch?v=jyK2paGYEgl&feature=c4-overview-vl&list=PLuyM9kxlfCq7COpOA68JY6msGBm9bJC_o
http://www.youtube.com/watch?v=jyK2paGYEgl&feature=c4-overview-vl&list=PLuyM9kxlfCq7COpOA68JY6msGBm9bJC_o

with perspectives from some of today’s leaders in the field.

Dr. Kevin Fickensher (AMIA): “This is the decade of informatics, where we will have the opportunity to transform healthcare. We are however in the very formative stages.”

Dr. Gil Kuperman (New York – Presbyterian Hospital) shared not his “predictions” of the future of informatics but more his “aspirations”. There are many innovations posed years ago (in the mid 1990s) that are still not widely disseminated. “The future of informatics is the same as the past – identifying and answering important questions”, such as: what’s the best thing to do with computers in healthcare? How can we use the data?

Dr. Rosemary Kennedy (Thomas Jefferson School of Nursing): The future of informatics is not just about Health IT, data representation and structure, the electronic health record, but any discussion about the future of informatics must also include public policy, organizational culture, finance and business models. Trends include: near continuous patient monitoring, rise in non-traditional sources of data (such as genomics data and use of nanotechnology), “big data” (which includes legal and ethical challenges), and empowering consumers by transforming health data into useful information.

Dr. Marc Overage (Siemens Healthcare): Informatics is beginning to “fork” more than previously – with both a divergence and focus in the theory and application of informatics. There are more clinician, non-informaticians who are taking the theory of informatics and applying it in many interesting and practical ways. However as EHR deployment becomes more widespread, it becomes more difficult to become more innovative in terms of research. Bringing the informatics solutions from other non-health disciplines to health informatics will become increasingly more important.

8. Scientific Paper Presentations

A signature feature of the symposium was a submitted abstract session entitled “Emerging Voices in Healthcare Informatics” that showcased innovative ideas in biomedical and health informatics approaches, theories and methods relevant to clinical and translational science. Papers were selected from a field of 55 abstract submissions in the areas of technical innovation, informatics research, data management, security, compliance, and ethics. Synopses of these very engaging and innovative presentations are detailed in the ► Appendix (available as supplementary file).

9. Conclusion: Cultivating Local Connections

The Symposium brings together healthcare professionals from diverse backgrounds in the Mid-Atlantic region and beyond to share their unique informatics perspectives. Adding the patient focus to the discussion this year provided the opportunity for everyone to assess their current practices and consider how they use informatics to not only provide improved patient care but also how to collaborate within their own organization and externally. Ideas and tools on how to use data more effectively including clinical decision support and a rethinking the power of the personal health record from the patient’s perspective using mobile technology drove home the central theme of this event.

Events like this symposium are a critical resource for regional healthcare informatics professionals. While informaticians are mindful of national and global developments and trends, those “practicing” applied clinical informatics actively exercise their informatics knowledge and skills in the real life settings of healthcare, academia, and industry. Learning takes place within these settings and with colleagues – through problem solving, dialoging, and networking – together. Regional informatics educational opportunities like the Mid-Atlantic Healthcare Informatics Symposium serve to not only enhance ongoing learning and collaborations but also connect local informatics efforts with national initiatives.

In fact, this Symposium and other ongoing educational efforts in the region have been a major catalyst in the formal establishment of the Mid-Atlantic Regional Chapter of AMIA, which was officially launched at the event. Long recognized as the professional home of informaticians and those engaged in the practice of informatics in the US, AMIA is underscoring the need of its members to foster activities that are important to local concerns and opportunities through the institution of a regional chapter structure. This trend in regionalization of informatics efforts will undoubtedly increase in the years to come, bringing the local practice of informatics more and more to the national spotlight.

Conflict of Interest

The authors declare that they have no conflicts of interest in the project or publication.

Human Subjects Protections

Human and/or animal subjects were not included in the project.

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