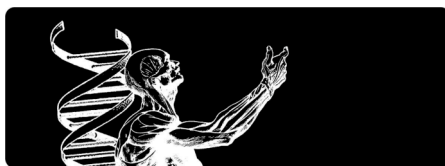


Friends of the National Library of Medicine

2010 Annual Conference

The ePatient: Digital and Genomic Technologies for Personalized Health Care



friends of the **National Library of Medicine**

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FNLM

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Overview

With the emergence of new digital and genetic technologies, scientific and medical advances make personalized healthcare not just an aspiration, but also a technical reality. The 2010 Annual Conference of the National Library of Medicine (NLM) and the Friends of the National Library of Medicine (FNLM) will bring together experts from technical, scientific, clinical healthcare, and theoretical perspectives to highlight emerging trends, scientific opportunities, and medical applications.

In order to generate new knowledge and a broader understanding of how application of new biomedical, data and communications technologies are transforming health care and how they will be evaluated, NLM and FNLM are focusing the 2010 annual conference on *The e-Patient: Digital and Genomic Technologies for Personalized Health Care*. In health care, the convergence of genomic, digital and wireless technologies is creating an exciting new era of potentials and possibilities in which patient criteria and data are prospectively health care drivers like never before. These developments are occurring as the demand for greater access to health care increases. Additionally, it is anticipated that new technologies will deliver both more effective health care and lower costs. Meanwhile, with government-funded incentives, digital technologies are becoming an essential, if not required, resource in health care delivery.

The *e-Patient* conference should effectively promote academic, industry and government interaction and reflect the NIH and NLM mission to release and process new information and knowledge. We anticipate participation and attendance by researchers, physicians, surgeons, medical and nursing school personnel, hospital and nursing home administrators, industry leaders, policymakers, health informaticians and other providers of health care services educators. Based on 2009 attendance, the target attendance is in the range of 400-500.

For the *e-Patient* conference, FNLM and NLM are also partnering with South Jersey Healthcare to offer continuing medical education (CME) credits to qualified recipients.

Thematic Workshops and Issues Addressed

The conference, titled *The e-Patient: Digital and Genomic Technologies for Personalized Health Care*, will include a series of workshop sessions on key issues related to technology strategies in today's patient care. Sessions as presently planned are listed below.

- **Comparative Effectiveness and Innovation:** To set the stage for the conference, the first discussion will focus on the political and budgetary realities of healthcare improvement. The introductory panel will review the role of comparative effectiveness studies in shaping health care delivery. Particular attention will be paid to the interactions between average care and personalized health care. As patient and health care delivery data have become digitalized, there have been growing opportunities to track outcomes by intervention, patient type, cost, and other factors. Yet, the scope, purposes and methods of comparing clinical effectiveness are only slowly evolving. There remains a tremendous opportunity to use data analysis to stimulate research and innovation especially on a targeted basis, but whether CER will be used to promote innovation and access to health care or a reason to deny coverage is a critical issue that will be reviewed in this session.
- **Health IT: Connectivity:** Faster and more effective exchange of health information will be necessary to personalize care and to control costs. The keynote speaker of the afternoon will review the numerous connectivity initiatives in health IT.
- **Health IT: Decision Support/Technologies:** Subsequent speakers and panels will review the latest advances in decision-support technologies to support personalized healthcare. The discussions will cover supporting clinicians as well as patient participation. Presentations will introduce not only the latest experimental results but also the business perspective on making such technologies widely available.
- **Industry panel:** This panel will discuss the implementation of Electronic Health Records and the opportunities brought about because of the new government stimulus policies in Health IT. This team of vendor experts has experience in deployment, implementation, integration, documentation, and training. They will describe the challenges associated with EHR implementation in unique healthcare environments.



- **Research 2.0: Social Networks for Health Research:** The convergence of personalized medicine and personalized electronic health records will bring changes in how clinical research is conducted and health care is provided. There will be changes in the roles of both health care providers and health care consumers as exemplified in an article in Nature Biotechnology in October 2009 on the use of social networking tools on the web for patient recruitment for clinical trials, “Can Web 2.0 reboot clinical trials?”. This panel will address the opportunities and challenges presented by this phenomenon.
- **Biomarkers in Cancer Research and Clinical Care:** The era of medicine custom-tailored to a patient’s genetic profile is nearly at hand in cancer research and treatment as progress is being made in the identification of biomarkers and their translation into the clinical research and treatment setting. Major initiatives are underway, for example, in tumor genotyping that will help set the stage for more targeted cancer-related research and treatment strategies as highlighted in an article in Science in October 2009, “Looking for a Target on Every Tumor.” This panel will address research in biomarkers with applications in cancer diagnostics and treatment in tandem with advances in the on-going development of personalized electronic health record databases.
- **Biomarkers in Brain Disorders Research and Clinical Care:** There are many challenges ahead in applications of personalized medicine to disorders of the nervous system. While advances continue apace in identifying biomarkers in a number of neurological disorders, their identification in neuro-psychiatric disorders have been more elusive. However, as evidenced at a meeting held in October 2009 on personalized medicine for the brain (Mayflower Action Report-Personalized Medicine @ <http://www.brainnet.net/>), laboratories around the world are working on neuro-psychiatric genomics that will advance making personalized medicine for the brain a reality. Personalized medicine with advances in neuroimaging and electronic health records databases will be the topic for this panel as exemplified by research in Alzheimer’s disease, Parkinsonism and autism.
- **Telemedicine/Mobile Health:** These panel sessions explore the fascinating ways that telecommunications and information technologies are changing the healthcare landscape now and in the coming years. These technologies, telehealth and mobile health, are no longer applied only to circumstances of remote access, but they are health care game changers by fundamentally altering the location and the temporal aspects of monitoring, assessing and reporting critical health information. In turn, the application and integration of these technologies, particularly when combined with access to patient health records, changes health care quality, personalization, access, and cost. The panel will include academic, clinical, industry and case information, including diabetes management using telehealth monitoring capabilities.

Conference Outcomes

Understand the types and differential characteristics of 1) genomic advances and their meaning for personalized healthcare and 2) electronic health records and digital and wireless applications. Identify priorities for the broader use, integration, and regulatory framework of these new technologies and compare them to provider, industry and patient perspectives. Incorporate these priorities into action recommendations particularly as they apply to comparative effectiveness research, personalized healthcare and research. A post-conference report will serve as a communication vehicle on advancements made at the conference and will promote continued participation and sharing of knowledge by industry leaders, policymakers, health informaticians, researchers and public health practitioners.

Benefits

The conference is addressing critical concerns in the realm of patient care at a very important moment in the planned transformation of healthcare record systems. A great deal of investment and a great deal of hope is weighted on these issues. Your organization’s participation and support would be recognized in a number of significant ways at the conference: in the program materials, on marketing materials, and with potential presence at the conference or conference reception or dinner. Please note that FNLM will gladly work with you to recognize your support, share in results and to coordinate your involvement. As you can see, the program has been planned independently by the FNLM conference planning committee and our partner organizations.

