Patient-centered care, collaboration, communication, and coordination: a report from AMIA’s 2013 Policy Meeting

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ABSTRACT

In alignment with a major shift toward patient-centered care as the model for improving care in our health system, informatics is transforming patient–provider relationships and overall care delivery. AMIA’s 2013 Health Policy Invitational was focused on examining existing challenges surrounding full engagement of the patient and crafting a research agenda and policy framework encouraging the use of informatics solutions to achieve this goal. The group tackled this challenge from educational, technical, and research perspectives. Recommendations include the need for consumer education regarding rights to data access, the need for consumers to access their health information in real time, and further research on effective methods to engage patients. This paper summarizes the meeting as well as the research agenda and policy recommendations prioritized among the invited experts and stakeholders.

Key words: patient-centered care, health information technology, health policy, data privacy, patient engagement

MEETING PURPOSE

To further a national understanding of how the future state of health, wellness, and care will increasingly include the active participation of patients, families, and caregivers through data use, re-use, stewardship, and governance in the delivery and management of patient-centered care, and to address the informatics-related challenges posed by the sharing and management of health data by developing recommendations on updates to current policies and establishing a research agenda.

INTRODUCTION

In 2001, the Institute of Medicine (IOM) defined patient-centered care as care that is respectful of and responsive to individual patient preferences, needs, and values and ensures that patient values guide all clinical decisions.¹ Patient engagement is critical to the success of enabling patient-centered care in the evolving healthcare landscape.² Engaged patients are individuals who actively seek to learn more about their own health and participate actively in its management.³ Typical patient engagement activities of relevance to the health informatics community include employing patient-generated data in the course of care, partnering with patients in data review, and using patient portals and other personal health information management tools. Informatics solutions provide the tools that allow for integration of health-related data at all points of care, from the institution to the community. Disease management systems, clinical decision aids, telemedicine, and other health information technology (HIT) applications have demonstrated a positive impact on the delivery of care.⁴ Resolving the informatics-related technical, social, and policy challenges will accelerate progress towards patient-centered care and lead to improved quality of healthcare and better health for all.

The American Medical Informatics Association annually convenes an invitational policy meeting to address complex issues such as those presented by a vision of patient-centered care. At the 8th Annual AMIA Health Policy Invitational Meeting, held in December of 2013, participants were challenged to examine and craft both policy recommendations and a research agenda that could enable data-driven, patient-centered care, collaboration, communication, and coordination. Stakeholders present included informaticians, providers, consulting firms, trade associations, government agencies, pharmaceutical companies, technology vendors, patient advocates, researchers, and patients. Presentations and breakout sessions, including those offering unique patient perspectives, fostered a greater understanding of efforts to promote patient-centered care and to surmount existing barriers arising from existing technical, social, and policy arenas. Many of the perspectives shared were framed in the context of a “learning health system,” where healthcare delivery aligns science and informatics, patient–clinician partnerships, incentives, and a culture of continuous improvement to produce the best care at lower cost.⁵
KEY THEMES OF THE 2013 AMIA HEALTH POLICY MEETING

Direct access to personal health data increases patient engagement and improves provider understanding, leading to a better patient experience.

For a patient to actively participate in the decision-making process, they must first acquire the necessary tools, including their personal health data which are located in many different repositories and electronic health records (EHRs). Legislative support for access to and protection of personal health data generated in the course of clinical care arises from two important laws: the Health Insurance Portability and Accountability Act (HIPAA) of 1996 and the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009 (updated 2013). The former established national privacy and security standards for the protection of certain health information, including data in electronic formats.6 The latter extended the groups that must comply with HIPAA standards, mandated data breach notification for patients, and extended patient access to data to include any electronic format they prefer.7,8

There is good evidence that direct access by patients to their health data, both data in the EHR and data generated by devices—such as self-reports on smartphones and sensors—can improve outcomes and decrease cost.9 Despite federal guidelines and regulations, patients continue to face challenges in accessing data generated in the course of clinical care, and also have concerns about the security, unauthorized access to, and accuracy of their personal health information within the EHR.10 Additionally, providers lack the time and tools to effectively integrate patient information from diverse sources.

In a patient-centered care model, privacy considerations become more complex, incorporating issues such as patients’ rights to choose to whom and for what purpose to disclose information, as well as how to preserve privacy in a care delivery model increasingly characterized by integrating information over time in support of continuity of care. New calls for clinical effectiveness studies necessitate the use of data generated in the course of care for research.

EHRs are necessary but not sufficient to engage patients and foster improvements in the quality of care.

The EHR, one component of which is the electronic medical record, remains a key and critical repository of health data. In addition, health-related data may be supplied from home-based monitors, by patient self-report and by sensor technologies. As healthcare moves into the community and the home, new and much larger sources of data related to health emerge. Some of these data are generated by and obtained directly from the patient, including self-monitoring of signs and symptoms as well as personal tracking of clinical observations, such as blood glucose. Other data come from previously unexpected sources, such as internet-based social media and patient support websites such as PatientsLikeMe. Thus, patient data are everywhere and their origins and volume are ever expanding.

Expanding the type of health information available to patients and clinicians brings special challenges. Patients need to do more than see words and numbers on paper or a computer screen; patients must understand what those words and numbers mean for them. Providers are challenged to appraise not only familiar physiological measures, but also the life histories and cultural identities of their patients. Providing the necessary data platforms to support engaging providers and patients in a patient-centered care model challenges the informatics community to build more sophisticated information presentation and management tools. In addition, patients should have the opportunity to identify and address errors in their electronic medical records.

Several tools exist to provide the data infrastructure for patient-centered care. The most mature and best understood of these is the EHR, which maintains data generated in the course of care delivery. A personal health record (PHR) is a suite of tools including an electronic collection of an individual’s health data and sets of utilities (or ‘apps’) that operate on those data.11 One emerging vision of the PHR is as a participatory care record, which allows for the storage of clinician-generated data and the creation and display of patient experiences and preferences. Patients can identify specific areas of need that are critical to understanding their specific preferences, which are afforded the same care-guiding benefits as clinical orders. With technology changing on a nearly daily basis, both patients and providers must be forward thinking in their approach to promote patient-centered care.

Workflow modifications and workforce development must accompany changes in the nature of health-related data, its generation, use, and storage, and the nature of health information technologies to support and manage the data. Providers need to adopt new in-visit behaviors so as not to let the technology come between them and their patients. Informatics solutions must instead be integrated into the natural flow of patient care. Patients require assistance to ensure health literacy and technological competence. Informatics specialists must understand the nature of this new, larger cadre of HIT users.

Health information needs to flow across the healthcare continuum.

Fragmented data within institution-specific EHRs interferes with the ability of patients, providers, and caregivers to develop a longitudinal view of the person’s health. Additionally, the lack of interoperability among systems causes frustration among all stakeholders. Yet, continuity of patient data across systems is essential to ensuring optimal patient care. Early third-party approaches to storing patient-generated information on commercial platforms such as Microsoft’s HealthVault12 and now-defunct Google Health13 are still struggling to find a foothold in the healthcare landscape.

With the context of care undergoing rapid change from the hospital and clinic to the home and community, data must be integrated and presented in a way that patients can understand, allowing for quality engagement with providers.14 Improved connectivity must include access to data, as well as patient–provider communication outside of the traditional care
settings. Consumer behavior research specifically targeting the support needed for patient-centered care could enhance the design and implementation of HIT solutions and can inform providers of new approaches to engage patients on their terms.

POLICY ISSUES AND A RESEARCH AGENDA
The invitational meeting discussions illuminated a number of policy issues that need to be addressed to improve access to one’s personal health information. Similarly, the analysis of the discussions resulted in the following research agenda that needs to be addressed through iterative exploration and testing in order to foster patient-centered care within the context of a learning health system:

1. What information from the EHR matters most to patients?
2. What usability and user experience efforts are required before systems are launched?
3. How can incentives be aligned to accelerate provider sharing of data with patients?
4. What are best practices in data-sharing with (1) other providers and (2) patients, families, and caregivers?
5. What best practices have been found for delivering online, culturally-relevant, accessible consumer health education?
6. What are the most effective models for patient engagement with care teams?

RECOMMENDATIONS

1. The Department of Health and Human Services (HHS) and the Office of the National Coordinator for Health IT (ONC) should adopt policies that create a robust health information infrastructure facilitating the ability of health systems to provide consumers with ready and complete access to their health information as soon as it becomes available.

2. AMIA should work with stakeholders including the Office of Civil Rights and HHS to educate health professionals and lay people on patients’ rights to full access to their health data and on the benefits of data sharing, including for the purposes of research. In its responsibility to health professionals, AMIA should work to establish strategies and policies that clarify clinician and health system responsibilities for data security as well as for broad-based health data sharing with patients.

3. ONC should collaborate with federal and private funding agencies to support research seeking to understand and address the patient experience of generating, accessing, analyzing, and using health data across the continuum of care. Funding agencies should direct particular attention to research involving patients holding a wide range of cultural identities, and those with physical or cognitive disabilities, low socioeconomic status, and low literacy, and should encourage research that involves patients in the context of their families and other caregivers.

4. ONC should explore policy and regulatory incentives (across federal agencies) to maximize and accelerate the use of innovative health information tools such as participatory care records, data platforms like Microsoft HealthVault, and sensor technologies.

SUMMARY
The 2013 AMIA Invitation Policy Meeting has set forth a vision of the data infrastructure needed to support patient-centered care. The EHR, in its present form, plays a key role as a repository of clinical data collected in the course of care, and policies should be enacted to support patients having full access to...
data in their EHRs as soon as the data are entered. New types of clinical information tools, such as PHRs and a sharable care record called a ‘Participatory Care Record,’ may accelerate patient engagement with the healthcare system as well as personal health management. As the importance of care across a continuum grows and is increasingly recognized, ONC should convene both policy makers and research funders to put in place the policy protections needed for broad-based, secure, and accurate data integration from multiple sources. Research is needed to ensure that the data collected are meaningful, understandable by patients, and aligned with the clinical workflow.

More information, including background materials and previous meeting reports can be found on AMIA’s website.¹⁶

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COMPETING INTERESTS
None.

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REFERENCES
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