ONLINE DISPUTE RESOLUTION IN A TECHNOLOGY-ORIENTED HEALTHCARE WORLD:

RESEARCH CHALLENGES

A Report on a Workshop held May 4-5, 2009

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EXECUTIVE SUMMARY

A great deal of attention has been given to efforts to improve the United States health care system by increasing the use of electronic health records (EHRs). Implicit in the plans to share electronic medical records among the health care community and with patients are new patient-provider dispute risks that can undermine medical and public confidence in the endeavor. The issues that are receiving the most public attention currently are privacy and legal liability from data breaches. Data quality problems, however, such as accuracy, comprehensiveness and clarity of the health care records have been largely unnoticed but are likely to vastly outnumber privacy disputes in frequency. The new-networked health information technology environments must address problems that rarely or never surfaced previously due to the inefficiencies and inaccessibility of paper-based record systems. Misunderstandings and mistakes must be corrected before they become complaints, complaints must be responded to before they become disputes, and disputes resolved before they become legal actions. Discovery of issues must become occasions for continuous improvement. It is time for a systematic effort to characterize the challenges and develop a responsive plan.

To address this need a workshop and follow on efforts were carried out with the following goals:

1. Identify the key risks of disputes in the networked health information technology systems being proposed.

2. Identify the best practices in avoiding and resolving such disputes and the need for new practices in open areas.

3. Identify the computing research challenges inherent in supporting these practices.

This report provides our conclusions and recommendations in these areas. Several conclusions from the workshop on how to engage dispute resolution to ameliorate the risks were summarized in postings made by John Halamka on his blog. Paraphrasing Halamka, the workshop concluded that:

1. There is a need to develop workflows for web-enabled dispute resolution processes. As the country implements more electronic records and shares more data, the healthcare world needs to embrace automated dispute resolution workflows such as are currently in use in many e-commerce contexts.
2. For issues that cannot be resolved via automated tools, an electronic escalation to an Ombudsman would be a reasonable alternative. Web applications could be used to support the ombudsman and help facilitate the process by identifying issues, managing the exchange of information, scheduling interactions, etc.

3. If there is an assertion of malpractice or harm caused to the patient, then workflows involving risk management and insurance organizations are appropriate.

In order, to achieve the workshop’s vision, a series of research activities are required.

1. Recommendation: Continue to support research to avoid privacy, data quality and misunderstanding.

2. Recommendation: Support research in online dispute resolution and prevention approaches and models that can be applied to a range of problems and disputes likely to arise in the networked electronic medical records environment.

3. Recommendation: Support research in the utility of computer forensic technology to preserve and enhance data quality of electronic medical records, with a special focus on the issues of data provenance.

4. Recommendation: Support research and evaluation of technological approaches to correcting and amending EHRs, while still preserving access to historical versions of the record.

5. Recommendation: Support research in methods of improving online patient-provider communication.
I. INTRODUCTION

A great deal of attention has been given to efforts to improve the United States health care system by increasing the use of electronic health records (EHRs). The benefits envisioned from widespread use of EHRs include improved patient care and support services, more efficient and accurate financial and administrative processes and, ultimately, quicker and more thorough responses to public health problems. Supporters hope to improve outcomes by avoiding errors, reducing delays, and providing better diagnoses. Projections of costs savings are substantial (Congressional Budget Office, 2008; DesRoches, 2009).

Implicit in the plans to share electronic medical records among the health care community and with patients are new patient-provider dispute risks that can undermine medical and public confidence in the endeavor. The issues that are receiving the most public attention currently are privacy and legal liability from data breaches. Data quality problems, however, such as accuracy, comprehensiveness and clarity of the health care records have been largely unnoticed but are likely to vastly outnumber privacy disputes in frequency. Such problems should be receiving attention and research to develop appropriate solutions using online tools should be initiated. Many such disputes can be anticipated, but with proper planning, investment in supporting research and technology, and the development of recommended “best practices” many will be avoided or ameliorated. (Sepucha, 2004; Brennan, 2010)

The new-networked health information technology environments must address problems that rarely or never surfaced previously due to the inefficiencies and inaccessibility of paper-based record systems. Misunderstandings and mistakes must be corrected before they become complaints, complaints must be responded to before they become disputes, and disputes resolved before they become legal actions. Discovery of issues must become occasions for continuous improvement. It is time for a systematic effort to characterize the challenges and develop a responsive plan.

To address this need a workshop and follow on efforts were carried out with the following goals:

4. Identify the key risks of disputes in the networked health information technology systems being proposed.

5. Identify the best practices in avoiding and resolving such disputes and the need for new practices in open areas.

6. Identify the computing research challenges inherent in supporting these practices.

This report provides our conclusions and recommendations in these areas.
II. **Key Risks**

Three key dispute risks in the new networked health information technology emerged: privacy, data quality and misunderstandings.

A **Privacy**

The public is already highly sensitized to the potential for breaches of privacy and the importance of developing resources to prevent the unauthorized dissemination of information needs no elaboration (Blumenthal, 2010; Office of the National Coordinator for Health Information Technology, 2008). Cases of theft of personal data are not uncommon and, thus, many mass-market publications have discussed this issue. The 2009 Health Information Technology for Economic and Clinical Health Act (HITECH Act) devoted one of its four subtitles to Privacy with extensive discussion of improved privacy provisions and security provisions. The Stage 1 Objectives for the Meaningful Use of electronic health records objectives originating from ONC includes as one of its five health outcomes policy priorities “ensure adequate privacy and security privacy and security protections for personal health information.” *(Federal Register, Jul 28, 2010; 75(144): 44370-44375)*

B **Data Quality**

Other potential areas of dispute have received much less attention. The data quality of medical records refers to a number of different dimensions along which the contents of records may be lacking (Markle Foundation, 2006). Table 1 gives the American Health Information Management’s Association definition (AHIMA, 1998) There is already evidence of significant challenges here. A survey of 35 studies beginning in 2004 concluded that patients and providers will be faced with far less than perfect data in their EHRs (Chan, 2010). The problems exist in areas where the data could conceivably be employed in making consequential decisions. On data completeness, the survey found that the preliminary evidence suggests that data quality within medication or problem lists were “mixed or poor:” “In the ambulatory setting, the omission rate for medication data was substantial across different clinical populations, from 27 percent of medications for ambulatory oncology patients to 53 percent for primary care patients.” A similar negative result emerged for accuracy: “All studies of medication lists report significant errors. A high proportion of patients, 81 percent and 95 percent reported in two studies, had errors in their medication list. Errors because of retention of discontinued medications were common, ranging between 13 percent and 29 percent across different patient populations. Incorrect medication regimens, less common at 5 percent to 14 percent, were also found.”
Unfortunately, this follows a period of considerable emphasis on avoiding adverse drug events (ADE) and improving patient safety in this area.

Recent survey data on personal health records conducted by Lake Research Partners found that “Making sure information is correct” is the number one feature portal users cited as useful and the main feature that current portal non-users indicated that they want access to (California HealthCare Foundation, 2010). It is reasonable to assume that as the number of patients accessing their records grows, that the data quality issues they encounter could lead to the sort of intense consumer reactions seen in credit card billing and credit reporting. This has resulted in both industries implementing online dispute resolution activities.

<table>
<thead>
<tr>
<th>ATTRIBUTE</th>
<th>DEFINITION</th>
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<tbody>
<tr>
<td>Data Accuracy</td>
<td>Data are the correct values and are valid.</td>
</tr>
<tr>
<td>Data Accessibility</td>
<td>Data items should be easily obtainable and legal to collect.</td>
</tr>
<tr>
<td>Data Comprehensiveness</td>
<td>All required data items are included. Ensure that the entire scope of the data is collected and document intentional limitations.</td>
</tr>
<tr>
<td>Data Consistency</td>
<td>The value of the data should be reliable and the same across applications.</td>
</tr>
<tr>
<td>Data Currency</td>
<td>The data should be up-to-date. A datum value is up-to-date if it is current for a specific point in time. It is outdated if it was current at some preceding time yet incorrect at a later time.</td>
</tr>
<tr>
<td>Data Definition</td>
<td>Clear definitions should be provided so that current and future data users will know what the data mean. Each data element should have clear meaning and acceptable values.</td>
</tr>
<tr>
<td>Data Granularity</td>
<td>The attributes and values of data should be defined at the correct level of detail.</td>
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<tr>
<td>Data Precision</td>
<td>Data values should be just large enough to support the application or...</td>
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Data Relevancy

The data are meaningful to the performance of the process or application for which they are collected.

Data Timeliness

Timeliness is determined by how the data are being used and their context.

Table 1. AHIMA Data Quality Criteria

Acknowledgement of these data quality risks is reflected in the Health Insurance Portability and Accountability Act (HIPAA) which states that “An individual has the right to have a covered entity amend protected health information or a record about the individual in a designated record set for as long as the protected health information is maintained in the designated record set (§164.526).” HIPAA applies to both paper and electronic records.

For electronic records, the Office of National Coordinator for Health Information Technologies (ONC) included a Correction Principle in its Nationwide Privacy and Security Framework for Electronic Exchange of Individually Identifiable Health Information. It states that “Individuals should be provided with a timely means to dispute the accuracy or integrity of their individually identifiable health information, and to have erroneous information corrected or to have a dispute documented if their requests are denied.” (Office of the National Coordinator for Health Information Technology, 2008)

Consistent with this, ONC has been advised by the Certification/Adoption Workgroup of its Health IT Policy Committee that with the right systems it should be possible to turn this right and interest into occasions to improve data quality:

Patient Engagement plays a major role in identifying errors and preventing problems. For example, in ambulatory settings, in nearly every encounter when it is possible for patients to observe and discuss information as it is entered during the health care encounter, potential errors can be avoided. Through a personal health record (PHR) or patient portal, patients obtain the ability to review some of the data in their EHR, and, as a result, PHRs and/or patient portals should continue to be encouraged. Access by family members to inpatient medication lists should also be encouraged (assuming appropriate authorization from the patient). Mechanisms that make it easier for patients to report inaccurate or questionable data need to be encouraged as “best practices.” Examples include (a) the use of a “feedback button” that makes it easy for a patient to communicate with and receive feedback about system problems, and (b) a secure communication link, perhaps through a PHR, that permits patients
C Health Literacy

A related issue involves responding to complaints that arise from misunderstandings or lack of understanding by the consumer of the data (National Network of Libraries of Medicine. 2010). Networked health information technology plans and “patient engagement” efforts will require that the general public be exposed to some of the complexity of medical data. The general level of health literacy for the average citizen falls well below the level required for general health care material. Many electronic medical records that patients will encounter in the networked health information environment were created for trained professionals. Unintentional misunderstandings will inevitably lead to disputes. The use of computing systems adds another level of complexity that has not existed before. For example, the proposals for consent agreements to allow electronic distribution of records without violating a patient’s privacy are certain to expose the patient to complex care processes shielded from him or her in the past.

The healthcare field has recognized the issues and challenges of health literacy. Efforts of long standing have gone into developing standard vocabularies and standards for electronic health records, which should reduce the burden. The Department of Health and Human Services has a “National Action Plan to Improve Health Literacy” and such an effort increases in importance as patients are exposed to more complex information than before (http://www.health.gov/communication/hlactionplan/pdf/Health_Literacy_Action_Plan.pdf accessed December 8, 2010).

III. BEST PRACTICES: ONLINE DISPUTE RESOLUTION FOR DATA QUALITY

Several conclusions from the workshop on how to engage dispute resolution to ameliorate the risks were summarized in postings made by John Halamka on his blog: Life as a Healthcare CIO (See Appendix D). Paraphrasing Halamka, the workshop concluded that:

4. There is a need to develop workflows for web-enabled dispute resolution processes. As the country implements more electronic records and shares more data, the healthcare world needs to embrace automated dispute resolution workflows such as are currently in use in many e-commerce contexts.

5. For issues that cannot be resolved via automated tools, an electronic escalation to an Ombudsman would be a reasonable alternative. Web applications could be used to
support the ombudsman and help facilitate the process by identifying issues, managing the exchange of information, scheduling interactions, etc.

6. If there is an assertion of malpractice or harm caused to the patient, then workflows involving risk management and insurance organizations are appropriate.

As Halamka states: “Thus, the work of the dispute resolution community working with the healthcare data community needs to think through the workflow that can be supported via web-based dispute resolution tools, while still ensuring the non-reputability of the medical record and complying with federal, state, and local medical record policies.”

The workshop took place more than a year before the issuance of “meaningful use” regulations for EHRs and the establishment of several requirements associated with patient engagement. It is also clear, at present, that this beginning effort, embodied in Stage 1 of “meaningful use,” is only a beginning. This is an understandable approach, given the resistance of physicians to adopt EHRs and their reluctance to communicate with patients using secure messaging due to concerns about time, reimbursement, and liability. Regulations for stages two and three will reveal how aggressively the goal of patient engagement will be pursued.

I. Research recommendations

In order, to achieve the workshops vision, a series of research activities are required.

1. Recommendation: Continue to support research aimed both at resolving and also at avoiding misunderstandings and disputes about healthcare data accuracy, privacy, and security.

Our concern is not only with the resolution of disputes but with preventing them and with identifying issues and problems before they become disputes. Avoiding disputes is preferable to resolving them, but both avoidance and resolution entail enhancing the accuracy, privacy and security of records. Our view is that powerful process definition, analysis, and execution technologies can be of fundamental value in both avoiding and resolving disputes over these kinds of issues. Once disputes arise, our experience has shown that Online Dispute Resolution (ODR) processes can be highly effective in orchestrating resolutions that are satisfactory to the disputant parties. Our view, further, is that these resolutions are likely to be facilitated by exploiting careful documentation of the way in which the various positions, proposals, etc. that form the basis for successful dispute resolution have been arrived at. Such documentation can be derived readily from analyses of appropriate ODR process definitions, which are then executed by sufficiently powerful process engines.
In addition, we suggest that the same process-driven ODR approaches to resolving disputes can and should be applied to the development of Electronic Healthcare Records (EHRs). This should have the effect of forestalling the development of systems whose defects and shortcomings could lead to potentially troublesome disputes about such issues as the structure, performance, and security of these systems and their data. Using process-driven ODR to resolve disputes about the nature of EHRs that are to be built should forestall many disputes arising from their use. Using appropriately powerful processes to effect process-driven ODR can result in the automatic documentation of how the resolution of these pre-implementation disputes was reached. The availability of this historical record should be effective in providing perspective on disputes arising during the use of the EHR, by acquainting disputants with agreements and rationales that could provide perspectives on the origins of dispute-causing behaviors. Indeed, we note that the desirability of identifying and reconciling different stakeholder interests during electronic medical record system development is completely consistent with the desirability of doing this generally in the development of all large software systems. Superior software and system development practice dictates that, typically, the development of such large-scale systems begins with a requirements analysis phase during which such stakeholder dispute resolution activities are carried out. That is because such resolution approaches are expected to be effective in assuring that the resulting system requirements are an effective basis for development of a system whose eventual performance and characteristics are agreeable to all stakeholders. Thus Software and System Engineering research and experience seems to support our position that processes that are effective in resolving disputes among EHR system stakeholders during EHR system requirements specification should help to avoid subsequent disputes about the electronic healthcare records that will eventually be managed by those systems.

All of these reasons suggest to us that robust technologies for supporting the definition, analysis, and execution of processes for supporting ODR could be most effective in both dealing with disputes and avoiding them. Previous work has shown that detailed definitions and analyses of healthcare processes can provide considerable value in identifying defects and vulnerabilities, and in supporting continuous process improvement leading to safer and more efficient healthcare (Osterweil 2010, Chen 2008, Clarke 2008). We now suggest that these same technologies can be similarly effective in developing EHRs in ways that avoid many disputes and expedite the resolution of still more disputes. But the development of sufficiently complete and precise healthcare process definitions turns out to be much harder than might be expected. Considerable ongoing research has been directed at the creation of process definition formalisms that are precise, detailed, and clear (Osterweil 2009, Wise 2006, Cass 2000). But more research is needed. Moreover, there is a particularly acute need for technologies aimed at analyzing processes defined using these notations to be sure that
those processes are free of defects, and can be expected to support executions that are robust and reliable (Clarke 2008, Chen 2008). Finally we note that it is important that these process notations be executable, so that the processes written in them can actually be carried out as defined. Very few of these process definition language are indeed executable. Thus, we conclude that the reduction of disputes surrounding electronic healthcare records can be reduced through the introduction of process definition, analysis, and execution technologies. But these technologies currently lack the maturity needed for effective support. That suggests that existing research efforts in process definition and analysis technology should be redoubled.

2. Recommendation: Support research in online dispute resolution and prevention approaches and models that can be applied to a range of problems and disputes likely to arise in the networked electronic medical records environment

In the early 1990s, when the Web first appeared, some hoped that the online world would be one in which conflict was rare. That had been the experience during the first twenty or so years of the Internet, a period when relatively few had access to it and the range of activities pursued was limited. During the early to mid-1990s, new capabilities for sharing and using information appeared, the ban on commercial activity online was lifted, opportunities for accessing information at a distance from both people and digital collections grew and barriers for publishing and distributing information widely were being lowered. As this occurred, the first wave of disputes, mostly involving spam, consumer purchases and copyright, also appeared.

All of the innovative online opportunities for using and communicating information that have emerged during the last two decades, however beneficial they have been, also opened new opportunities for conflict. Lifting constraints that existed in an age when information was in physical form and in physical places also lifted barriers that had made it difficult, inconvenient, and costly to use such information in a harmful or illegal manner. For example, as it became easy to distribute information in digital form, it also became easy to share copyrighted information and as it became possible to create an identity online, it also became possible to steal others’ identities.

The field of online dispute resolution emerged in the late 1990s as it was recognized that environments that are highly active, that generate large numbers of transactions, that facilitate the formation of new kinds of relationships and make possible interactions among people in different countries and cultures, will also generate disputes (Katsh, 2001). Online
companies, such as eBay, and Internet-related entities, such as the Internet Corporation for Assigned Names and Numbers (ICANN), recognized this and each put into place an online process for handling disputes. Today eBay handles over 60 million disputes a year with a relatively small in house staff. eBay’s methods have significantly more capabilities for assisting users than any processes found in patient portals to assist patients.

The new environment of patient-accessible health records not only opens up new opportunities to design processes for resolving disputes but, perhaps more importantly, will allow research into how disputes arise and how they might be prevented. Several decades ago, William Felstiner, Richard Abel and Austin Sarat characterized the process of dispute formation as “naming, blaming and claiming (Felstiner, 1981).”

The three categories relate to the “way in which experiences become grievances, grievances become disputes, and disputes take various shapes.” The study of the disputing end of the continuum, which may involve litigation or one of the alternative dispute resolution processes, has received the most attention from scholars. The earlier stages of naming, where an individual perceives something injurious, and blaming, where a person attributes fault, have received much less attention (Katsh, forthcoming).

These categories reveal that while dispute resolution processes are needed at the disputing end of the continuum, dispute prevention efforts are appropriate and needed at the naming and blaming end. In the physical world, resolution processes receive more attention because disputes are more visible and focused than the feelings of dissatisfaction or even anger that is typical of the earlier stages. Very little is known about “blaming” and even less about “naming” since whatever concerns arise are rarely communicated to those who, at a later stage, might be held responsible for the problem.

Research on EHR systems should enable us to understand more clearly the life cycle of a dispute. Options for identifying a problem and complaining or alerting others about it may be more possible when there are effective communications options at the naming and claiming stages. In a field that is highly concerned with malpractice and medical liability, it is particularly important to “channel disagreements into a problem-solving arena early enough [so] that escalation into full-blown disputes can often be avoided (Costantino, 1995).”

EHRs are an appropriate context in which to ask about new opportunities to prevent and resolve disputes because there are clear analogies to the issues involved in preventing and treating illness. The field of preventive medicine has grown as capabilities for identifying
symptoms and conditions have become more and more powerful. There will probably never be as much objective data about a deteriorating relationship as there is about an incipient medical problem but those interested in information-based dispute prevention should be able to learn from the experience of preventive medicine about the challenges in effectively and appropriately using data for prevention purposes.

Attendees at the workshop and others we have interviewed have urged us to avoid the use of the word “dispute” as much as possible and to emphasize that “naming, blaming and claiming” are a continuum along which problems occur and need to be addressed more than they are discrete stages. This is a view that is somewhat at odds with dispute resolution research in the physical environment but it is also one that suggests that there are new approaches and areas of research in an electronic environment.

Having accepted dispute resolution as a challenge, technology must be available to deal with disputes promptly and effectively. There are a reasonably large number of models for dispute resolution in this area to choose from. These vary from software-assisted negotiation without a third party to present to processes in which a mediator is present and technology plays the role of a “fourth party,” a concept suggesting that software can enhance the capabilities of the mediator for managing communication and the processing and evaluating of information. In all these approaches are opportunities to facilitate brainstorming, identify interests, generate options, rank and vote, and discuss and reach consensus or make a decision. In short, there is much technology to be investigated in applying online dispute resolution to electronic medical records environments.

3. **Recommendation: Support research in the utility of computer forensic technology to preserve and enhance data quality of electronic medical records, with a special focus on the issues of data provenance.**

In order to facilitate effective dispute resolution, it is necessary to understand the roots of a grievance. For example, has a security breach occurred or is data incorrect? This is often referred to as Computer Forensics, which the United States Computer Emergency Readiness Team defines as “the discipline that combines elements of law and computer science to collect and analyze data from computer systems, networks, wireless communications, and storage devices in a way that is admissible as evidence in a court of law.” (http://www.us-cert.gov/reading_room/forensics.pdf)

Technology in this area for electronic medical records has focused more on privacy and security than on data quality issues. Data quality in the world of interoperable records presents special problems since the source of the data may be from outside the organization
presenting the information to the patient (Hoffman, 2009). In such instances, audit trails are crucial. Audit trails involve the recording of who did what to whom, when, and in what sequence. They have been used to satisfy system integrity, recoverability, auditing, and security requirements. As will be seen, these developments are also necessary to facilitate the changing and correction of electronic medical records.

The value of information will vary depending upon how well the source of the information is understood. Data that is accompanied by no information about its source (its provenance) is vulnerable to doubt and criticism. This seems to be particularly true of data that a patient views in his or her electronic health record. Such data can be surprising, even shocking. Especially in such cases, electronic health record data is far more valuable when its source is known. At the least the source of comments, diagnoses, and observations should be annotated by audit trail data in the form of provenance metadata, namely data about the source or sources of data. In its simplest form, provenance metadata might contain a record of the date and time at which the data was generated, and it would presumably be easy to provide and attach this metadata as an annotation to the original data.

Metadata, however, may need to be far more complicated. Thus, for example, a diagnosis may be based upon examination of a large amount of data of different kinds (e.g. test results, graphic images, physician notes, etc.). Attaching metadata annotations of this sort is far more challenging. Going further these test results, images, and notes may themselves be derived from still other data items. The full historical trace of the evolution of key data items in an electronic health record might be long and complicated, and indeed might be even more significant than the final data itself. Thus, for example, a diagnosis is presumably a data item of great importance, but a provenance history, indicating how the diagnosis was reached, adds enormous value and may indeed be of more interest and importance than the diagnosis itself.

Requests for amendments can go well beyond diagnostic issues. It has been pointed out to us that in cases where requests for modifications have been ultimately denied it is important to have a detailed history of the source of the data. These cases often originally arise in emergency rooms where the records affect future insurance claims. Appropriate audit trails and data provenance metadata can ease the burden of resolving these disputes.

We suggest that it is important to initiate a program of research into how to annotate the data in electronic health records with appropriate audit trials and provenance metadata. Existing approaches seem to either use database concepts and methods, or process technologies and approaches, as the basis for creating and using provenance metadata. Both seem to have aspects that could make them particularly effective in the healthcare domain.
Research is needed to help determine how to select from, or synergize, these approaches for this domain.

The recent President’s Council of Advisors on Science and Technology report on the potential makes very similar points for different reasons (PSAT, 2010). They conclude that there is crucial need for the adoption of a universal exchange language for healthcare information using meta-tagged data elements. They want physicians to be able to dig deeper when false positives appear in clinic tests, among other goals. The call for elements to include “the provenance of the data—the date, time, type of equipment used, personnel (physician, nurse, or technician),” We agree.

4. **Recommendation: Support research and evaluation of technological approaches to correcting and amending EHRs, while still preserving access to historical versions of the record.**

In order to prevent or resolve a dispute, it will often be necessary to “correct” the situation that caused the dispute – correct and modify records, improve data quality and reduce the cause of a misunderstanding. This presents challenges in the healthcare domain because of the nature of the data flows and the laws, regulations and liabilities associated with health records (Katsh, to appear).

With respect to the data flows, as noted above, the patient sees data that is derived from initial sources. It may not be displayed as it was when it was initially recorded. A single value may be the combination of a variety of primary data entries. The material displayed is very likely to be a selected subset of the full data concerning the patient. Resolving a dispute involving data quality may involve “unpacking” and “repacking” complex information. Given the criticality of this data, performing these corrections deserves well-defined, trustworthy methods.

At the same time, in a networked healthcare world the electronic medical records data may have been distributed to other sites for further use. Correcting data in these cases is a significant challenge. There have been cases of errors that have been corrected many times still remaining in records. Technology is needed to manage these issues.

Provenance metadata, especially provenance metadata that incorporates historical derivation trace information, could be particularly valuable in cases where some data is found to be incorrect, or should be supplanted by newer or more accurate data. In such cases it may be particularly useful to document the impact of such changes by identifying other data items upon which the supplanted was based and those based on the data in question. This could
then be used to expedite the process of reconsidering, re-computing, or replacing such consequent derived data items.

The challenge of “correcting” medical records is exacerbated by the requirement of legal discovery that requires that no data be deleted from a record. The healthcare community in the era of paper medical records accepted that nothing could be deleted from a file and generally adopted a policy of annotating data by stapling, affixing, or appending a statement explaining an error. It was not an area of controversy, since relatively few requests to amend were requested, and it was not a process that needed clarification, for much the same reason. Exactly how best to add new material or correct old material in an electronic medical record, however, needs to be studied and, perhaps, standardized.

Examples based on the paper model of appending information appear ineffective. One case changed a mistaken record of gender by putting the corrected gender several screens down at the end of the complete record. There are many options for how a correction might appear on the screen. Representing change on the screen can be done in different ways, such as crossing out the old, putting the old in a different color, or providing a link to the old so that it does not clutter the screen. Research needs to be performed so that standards and policies can be developed and propagated.

5. **Recommendation: Support research in methods of improving online patient-provider communication**

Broader implementation of EHRs requires research into how to optimally use online communication between patient and provider. For example, the literature reports examples of technology for improving data quality that provided better information that that contained in the medical record and yet the records were not corrected (Staroselsky, 2008; Tarn, 2009). This may differ depending on the type of data. For example, allergies are hard for patients to differentiate from drug side effects. Monitoring usage will also allow discovery of new issues in the use of electronic medical records through discovery of the nature of the patient-provider disputes. Monitoring of the success of online dispute resolution will also be required before being able to put it forward as a best practice and to advocate for its general adoption.

Finally, problems in addition to privacy, data quality and misunderstandings are likely to emerge. Misunderstandings may be related not just to a patient’s lack of understanding but to a provider’s misunderstanding what the patient was attempting to convey to the provider. A patient’s attempt to correct data may similarly represent an attempt to convey something beyond the accuracy of the record to the provider. An update to a problem list may be a
patient’s effort to communicate a change in condition, to give the provider information she
did not provide during a visit, to alert the doctor about a possible side effect from a new
medication, or for many other reasons. A correction to a medication list could be out of
concern for possible drug interactions, to help the provider understand symptoms, or to
check to see if the patient is following a care regimen successfully. Providers shape care
giving so information from patients may represent an opportunity to evaluate the
effectiveness of a care plan, to change a medication, to identify a new symptom that could
clarify a diagnosis, and to learn how and why discharge instructions were misunderstood.
The patient-provider interaction is a mutual attempt to make sense of conditions, care plan,
diagnosis, and other concerns. Theories and models for online patient-provider
communication should be developed that encompass these needs.

IV. CONCLUSIONS: IMPLEMENTING THE RESEARCH AGENDA

It is essential to mount a new research initiative to prepare for the disputes that will
inevitably arise with the introduction of electronic health record systems and their exposure
to patients. This initiative must advance computing and information technology, social
science and health care methods. This initiative will address a critical need for the
acceptance and the effectiveness of health information technology. Most significantly, it will
help that technology achieve the improvements in the quality, safety and cost effectiveness
of health care which society urgently needs.
REFERENCES


Coordinator for Health Information Technology, U.S. Department of Health and Human Services.


PCAST 2010: Report To The President Realizing The Full Potential Of Health Information Technology To Improve Healthcare For Americans: The Path Forward, Executive Office of the President’s Council of Advisors on Science and Technology December 2010.


Wise 2006: Little-JIL 1.5 Language Report, Alexander Wise, Department of Computer Science, University of Massachusetts, Amherst, MA 01003, October 2006.
ACKNOWLEDGMENTS

This workshop arose out of a challenge made by Larry Brandt of the Digital Government Program of the National Science Foundation to the organizers and our long term research partner, Daniel Rainey of the National Mediation Board, to identify the research issues facing the next set of challenges facing Online Dispute Resolution. We enlisted Dr. John Halamka of Harvard Medical School and CareGroup Healthcare System to help us focus on the technology-oriented healthcare world that is emerging. Together we solicited the support of Jodi Daniel and Steve Posnack of the Office of the National Coordinator for Health Information Technology who agreed to join the NSF and NMB in funding the workshop. ¹

We worked closely with Leah Wing, University of Massachusetts Amherst, to create the invitation list. Deb Bergeron made the meeting arrangements. Michelle Sagan Gonçalves prepared our website. Don Mon and David Sweet of the American Health Information Management Association generously supplied a wealth of read ahead material. Harry R. Hoglander, Chairman of the National Mediation Board, kindly welcomed us to NMB’s facilities. Beth Noveck, United States Deputy Chief Technology Officer and Director, White House Open Government Initiative, joined us to describe the Initiative.

The greatest possible thanks must be reserved for the attendees who gave generously of their time. All participants deserve credit for their active participation and creative contributions.

¹ This material is based upon work supported by the National Science Foundation under Grant No. 0840248. Any opinions, findings, and conclusions or recommendations expressed in this material are those of the authors and do not necessarily reflect the views of the National Science Foundation, the Office of the National Coordinator for Health information technology or the National Mediation Board.
APPENDIX A. ONLINE DISPUTE RESOLUTION IN A TECHNOLOGY-ORIENTED WORLD WORKSHOP

Goals

The program followed the workshop goals to:

I. Identify the key risks of disputes in the networked health information technology environment.

II. Identify the best practices in avoiding and resolving such disputes and the need for new dispute prevention/resolution approaches in problem areas.

III. Identify the computing and other research challenges inherent in supporting these practices.

Tuesday, May 5, 2009

The Tuesday May 5th session focused on meeting the first two goals identified above through open discussion and brainstorming.

Location: The Madison, a Loews Hotel

Schedule:

8:00 AM - Continental breakfast

9:00 AM - Workshop Opening

12:00 PM - Working Lunch

5:00 PM - Workshop Closing

6:00 PM - Reception and working dinner at the Madison Hotel.

Speaker: Beth Noveck, Deputy Director for Open Government, Office of Science and Technology Policy, Executive Office of the President
Wednesday, May 6, 2009

The Wednesday, May 6th session focused on meeting the third goal identified above.

**Location:** The National Mediation Board

**Schedule:**

- 9:00 AM - Workshop opening
- 12:00 PM - Workshop closing
APPENDIX B: WORKSHOP ATTENDEES

Organizers:

• Ethan Katsh, National Center for Technology and Dispute Resolution, University of Massachusetts Amherst
• Norman Sondheimer, Electronic Enterprise Institute, University of Massachusetts Amherst
• Leon Osterweil, Electronic Enterprise Institute, University of Massachusetts Amherst
• Lori Clarke, Department of Computer Science, University of Massachusetts Amherst
• John Halamka, CareGroup Health System and Harvard Medical School

Dispute Resolution

• Kirk Emerson, University of Arizona
• Joshua Gordon, Part of the Solution, ADR Services
• Deborah Laufer, U.S. Air Force
• Troy Morgan, GE Healthcare
• Daniel Rainey, National Mediation Board
• Janet Rifkin, National Center for Technology and Dispute Resolution, University of Massachusetts Amherst
• Colin Rule, eBay and PayPal
• Leah Wing, National Center for Technology and Dispute Resolution, University of Massachusetts Amherst

Computer Science

• Larry Brandt, National Science Foundation
• Noshir Contractor, Northwestern University
• Artur Dubrawski, Carnegie Mellon University
• Ed Durfee, University of Michigan
• Lee Giles, Penn State University
• Carl Gunter, University of Illinois
• Andy Podgurski, Case Western Reserve University
Healthcare

- MSG Michael Caldwell, Army Medical Command
- Vizma Carver, ONC/NHIN
- Scott Cooper, ANSI
- Jodi Daniels, Department of Health and Human Services
- Teresa Foley, Army Medical Command
- Dr. John Halamka, Harvard Medical School and Beth Israel Deaconess Hospital
- Glen Marshall, Healthcare Information Technology Standards Panel
- Deven McGraw, Center for Democracy & Technology
- Steve Posnack, Department of Health and Human Services
- Joy Pritts, Georgetown University
- Walter Suarez, Public Health Data Standards Consortium
- Stefan Verhulst, Markle Foundation
- Lydia Washington, American Health Information Management Association
APPENDIX C: FOLLOW-ON INTERVIEWS

- Beth Israel Deaconess Medical Center: John Halamka, Margaret Jeddry
- Children’s Hospital Boston: Fabienne Bourgeois, Ken Mandl
- Geisinger Health System: Jim Walker
- Kaiser Permanente: Kate Christensen, David McWaters, Peter Richter, Anna-Lisa Silvestre
- Palo Alto Medical Foundation: Paul Tang
- Partners HealthCare System: Jonathan Wald
- Veterans Affairs: Susan Woods
APPENDIX D. “LIFE AS A HEALTHCARE CIO” ENTRIES

The co-organizer Dr. John Halamka maintains a blog: Life as a Healthcare CIO. Here are two entries related to our workshop, one proceeding and one following it.

MONDAY, APRIL 27, 2009

Dispute Resolution in Healthcare

At the recent Health 2.0 conference, I was asked an interesting question. If there is a dispute about any data in healthcare - PHR, EHR, or Health Information Exchange, how is it resolved?

eBay does millions of transactions via the internet and it has automated, web-based dispute resolution workflows. Can healthcare learn something from eBay?

On May 5, I will be attending a workshop in Washington called "Online Dispute Resolution in a Technology-oriented Healthcare World.”

The attendees are evenly split between representatives of the Healthcare, Dispute Resolution and Computer Science communities.

The goals of the meeting are:

*Identify the key risks of disputes in the networked health information technology environment.

*Identify the best practices in avoiding and resolving such disputes and the need for new dispute prevention/resolution approaches in problem areas.

*Identify the computing and other research challenges inherent in supporting these practices.

You'll find a list of attendees and the conference background materials online.

As the recent work with I've done with e-Patient Dave illustrates, Personal Health Records should have a process for resolving data issues. If such a feature would have been built into Patientsite, Google Health or Microsoft Health, we might have identified the issues with administrative data and PHRs sooner.

I will report back next week with lessons learned from the conference, included recommended next steps for the software we use with patients at BIDMC.
FRIDAY, MAY 8, 2009

**Follow up on Dispute Resolution**

In my earlier blog about Dispute Resolution, I described the planned gathering of computer scientists, electronic health record experts, and dispute resolution professionals called 'Online Dispute Resolution in a Technology-oriented Healthcare World'

I attended the event and enjoyed the multidisciplinary discussion, learning a great deal about possible disputes among the data stakeholders in healthcare - patients, providers, payers, employers, compliance organizations, public health, government, national security, research etc.

Here are a few lessons learned:

1. There's a need to web enable dispute workflow in healthcare. As e-patient Dave pointed out, I did not hear about any data concerns regarding personal health records likely because there was no easy way to raise the issue. Hospitals have policies regarding medical record disputes. Generally the workflow involves writing letters, making phone calls, and resolving disputes via committee. As the country implements more electronic records and shares more data (with patient consent), among more stakeholders, we need to embrace automated dispute resolution workflows such as are used by eBay. In healthcare, the issues are complex because the medical record is a legal record and there are many compliance issues involved in annotating it. However, I can imagine adding a comment field to the problem list which could be electronically annotated by the patient, so a clinician examining the record could understand the patient's point of view if data is disputed. In our medication reconciliation application, we give clinicians the ability to make notations about patient compliance with medications i.e. discontinued, taken infrequently, changed to a different medication etc. I can imagine gathering this input directly from patients.

Thus, the work of the dispute resolution community working with the healthcare data community will be to think through the workflow that can be supported via web-based dispute resolution tools, while still ensuring the non-repudiability of the medical record and complying with federal, state, and local medical record policies.

2. For issues that cannot be resolved via automated tools, an electronic escalation to an Ombudsman is a reasonable workflow. Complex issues are generally more easily resolved when two people speak directly rather than virtually. However, a web application could be used to identify the issues, exchange background information, and schedule the discussion.
3. If there is assertion of malpractice or harm caused to the patient, then workflows involving risk management and insurance organizations are appropriate.

The full report of the meeting will be available soon, but in the meantime, I will be more sensitive to the need to consider the modes of failure in electronic health records, especially those which are shared with patients, and the desirability of automated dispute resolution workflow.