

Viewpoint Paper ■

Informatics Challenges for the Impending Patient Information Explosion

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Abstract As we move toward an era when health information is more readily accessible and transferable, there are several issues that will arise. This article addresses the challenges of information filtering, context-sensitive decision support, legal and ethical guidelines regarding obligations to obtain and use the information, aligning patient and health professionals' expectations in regard to the use and usefulness of the information, and enhancing data reliability. The authors discuss the issues and offer suggestions for addressing them.

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The next ten years have great potential to be a golden age for health informatics. A confluence of forces including improved technology, government support, and physician and patient receptivity to the benefits of information technology are likely to lead to increased use of health information technology.¹ The goal of all clinicians using electronic medical records, patients having personal health records, and electronic health records (EHRs) that will be accessible whenever and wherever the information is needed, finally has a chance of being realized.² When that occurs, clinicians will have more information than ever at their fingertips. In the informatics community, the emphasis has tended to be on the advantages of having more information available for decision making. What may not be fully appreciated is that along with these benefits comes an increased need for information filtering, context-sensitive decision support, legal and ethical guidelines regarding obligations to obtain and use the information, aligning patient and health professionals' expectations in regard to the use and usefulness of the information, and enhancing data accuracy.

Information Filtering

Concern about the information explosion in regard to biomedical information has long been recognized. The Internet and the World Wide Web have increased the need for quality filtering of information for both clinicians and patients as more and more medical information is made accessible.³ In addition to the development of intelligent search mechanisms, compilations of evidence-based research such as the Cochrane database (<http://www.cochrane.org/>), services such as Up-to-Date (www.uptodate.com), and other similar summaries of evidence are available.

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Because patient information has traditionally been incomplete and fragmented, the informatics community has focused on the benefits of complete and accessible information that the lifelong EHR will bring. What has not received enough attention is that coupled with the extensive information will be a need for the development of filtering mechanisms. Informal filtering and summarizing of information are actually built into today's health care practices, where there is even less information potentially available. Similar strategies, human or computer based, will be needed even more in the future if clinicians are not to be overwhelmed by the "patient information explosion."

There are many examples of such filtering. Handoffs during changes of shift, while prone to error because of incomplete information and communication failures, when done well, alert the incoming clinician to the most pressing problems and areas of major concern. In settings in which we today have a large volume of information, such as intensive care units, despite the availability of multiple information sources, the physician typically asks the nurse to summarize what is going on with the patient. In this case, it is not absence of information that is the problem, but the presence of too much information that needs to be integrated in a limited amount of time.

When clinicians summarize patient information for other patient care team members, they automatically structure the information for the specific individual. Summaries are expanded or abbreviated to accommodate the team member's level of experience, role, or knowledge of the individual patient. For example, a physician on-call may need a more complete version of the patient's status than one who just saw the patient the day before. Nurses require different patient information than physicians, who require different information than physical therapists. Even within the same specialty area, information needs vary by context.⁴ Tailoring information delivery can eliminate the need for clinicians to sift through superfluous information, increase user satisfaction, and decrease unnecessary access to confidential patient information.

Time pressures are only part of the reason for needing summaries of information. Human information-processing capabilities also demand a mechanism for filtering information.

Traditional medical education teaches physicians that they must make judgments under uncertainty, that they will never have all the information that they would like, and that they must develop decision-making strategies to optimize decision making under these conditions. We assume that decision making with more complete information will be better, but simply having the information available will not guarantee that it is properly used, and too much information could potentially confuse rather than enlighten. For example, increasing the volume of data may necessitate changes in protocols for dealing with abnormalities. For instance, by using telemonitoring devices, volumes of electronically collected patient data can be transmitted to home health nurses who previously collected these data intermittently. Where in the past physicians were notified of any abnormal blood pressure reading, to avoid overwhelming them with information, now the physician might only be alerted when the system records three or more abnormal values in a specified time period.

With a complete EHR, despite, or perhaps because of, the amount of information available, the need for summarizing key information and alerting the clinician may be even more important. With an increased volume of information, it may be more difficult for the clinician to read, process, and filter. As the medical informatics community promotes the development and use of EHRs, we should incorporate the principles of cognitive and human factors research in terms of display of information, continuing to use our informatics expertise to develop the search, filtering, and summarizing tools that will be needed.^{5,6}

Context-sensitive Decision Support

Clinical decision support systems (CDSSs) have been shown to improve patient safety and to reduce the cost of care.⁷ These tools, developed by informatics researchers over the past 40 years, coupled with electronic medical records, have great potential to dramatically improve health care quality. In fact, many of them, such as the diagnostic programs, could serve the summarizing and integrating functions that will be needed. However, while these tools have the potential to improve care, problems have begun to surface regarding their proper use. Studies have shown that, although information systems have the capability of sophisticated decision support, these capabilities are often not used. Drug alerts are frequently overridden,⁸ turned off, or are set at a very high threshold so that clinicians are alerted to only the most dangerous interactions. Evidence-based computer suggestions are also frequently ignored, ostensibly because they are not sensitive to the needs of the individual patient.⁹ Research has shown that with some of the diagnostic decision support programs, clinicians do not always heed their correct advice, in part because of overconfidence and in part because it may be difficult to distinguish correct from incorrect advice.^{10,11} Not only do such practices raise ethical and legal questions, they mean that the full benefits of the systems will not be realized.

A major reason why these systems are not used optimally is that while we have developed tools to take electronic patient information and provide alerts and suggestions based on the information, we have not refined these tools to the point where they provide advice that is more likely to be heeded. Users may be more likely to accept guideline recommendations if they understand the rationale behind them. Com-

binning decision support with explanation services providing definitions, rationale, and evidence-based guidelines could increase confidence in system recommendations.¹²

However, agreement in principle with a guideline still may not ensure its use. Just as there is a need to filter patient information, there is also a need to filter the alerts and reminders that CDSSs can provide. Turning off alerts for all but the most severe drug interactions is basically a crude attempt to avoid "alert fatigue."^{13,14} Approaches such as multilevel alert tiers have been recommended as a strategy to avoid alert fatigue.¹⁴ With more information available in an electronic record, we should also be able to develop what might be called context-sensitive decision support. The development of info-buttons¹⁵ and other types of context-sensitive links¹⁶ are examples of such tailored information delivery.

Context-sensitive decision support might also involve an even more nuanced approach. For instance, rather than turning on only the most dangerous drug interaction alerts to avoid overwhelming the clinician, we might turn on all alerts for particularly vulnerable patients, such as the elderly, while leaving only the high-risk alerts on for lower risk patients. Similarly, diagnostic programs could operate in the background and be available for review, but would only function to alert the physician under certain conditions. They might provide active suggestions for diagnoses not considered only when it is clear from the proposed workup orders that a significant procedure is left out or is clearly unnecessary.¹⁷ To implement context-sensitive decision support, the choice and use of CDSSs would be more complicated and existing systems might have to be redesigned, but the outcome might be better attention to, and utilization of, the information.

Ethical and Legal Guidelines

In anticipation of having all of a patient's information easily accessible, there is a need to begin to develop guidelines for use of the information when it is available. How much of a patient's "lifelong medical record" is the physician obligated to obtain and review? Which care team members will have access to which parts of the EHR and who controls this access? Traditionally, providers and health care institutions have controlled the collection of and access to patient data. However, there is increasing advocacy for patient control of patient information. Under this paradigm, patients could grant one-time-read-only access, emergency only access, access of certain portions of the record for specific providers, and the assignment of another who could act as a deputy for minors or the impaired.¹⁸

Having access to records that have previously been held in individual practice offices may raise sensitive professional differences between providers. What obligation does a physician have when confronted with evidence of what he or she considers inadequate treatment documented in the EHR? A study that provided physicians with access to patients' full medication history, including medications currently prescribed by other physicians, found that physicians were reluctant to override decisions made by other physicians and discontinue medication, even when alerts indicated problems with the medication.¹⁹ Perhaps each case will have to be handled individually, but attention should be given to delineating clinician obligations when they can have access to information previously unavailable.

Accuracy of Information

Primary care providers are currently expected to coordinate a patient's care, yet there are data showing that currently there is great deal of missing information in primary care settings.²⁰ We assume that having the information from other laboratories and other clinicians will reduce repeat testing and will inform decision making. While this will probably occur, concerns about the accuracy of the information may still be an issue. These concerns are not unique to EHRs, but generally today, the amount of information that is available to the physician is much smaller than it would be with full access to all of a patient's previous medical records. Even so, repeat test ordering because of lack of trust in the previous provider's data or diagnoses is not unusual.

Accuracy of system documentation is usually calculated using two measures: the proportion of documented observations in the system that are correct (correctness) and the proportion of observations that are documented (completeness).²¹ Judging the correctness and completeness of collected patient data is a difficult process even when we are familiar with the system in which it was collected. Lifelong medical records will contain information collected in different locations, by people with varying medical expertise, and probably descriptions of treatment modalities and test data that will seem outmoded when accessed at some point in the future. Determining data accuracy becomes problematic when we have no knowledge of where or by whom the data were entered. These issues provide even more impetus toward implementing terminology and minimal data set standards that will help practitioners judge the quality of the EHR data that they are reviewing.

In some form, this record will also include data entered by patients. Patients have been seen as increasing and decreasing the accuracy of data collected. In a study of the accuracy of medication data in an outpatient electronic medical record, patients were found to be the major cause of error, accounting for 36% of the recorded errors.²² In another study, consultation with patients increased the completeness of the medical record problem list by 28%.²³ Patients did not have direct access to the information system in either study. Patient-reported data were only entered into the system when the patient or outside provider had contact with one of the office staff. Perhaps with universal access to the information record and timely patient data entry, this error rate could be reduced. Other interventions that have been shown to improve accuracy include direct physician entry,²⁴ structured encounter forms,²⁵ anticipatory prompts,²⁶ periodic accuracy monitoring and feedback,²⁷ and automated data capture from patient information systems.²⁸ The accuracy of patient-entered data may also depend on the match between the interface and the type of information entered. For example, information with more opportunity for error or confusion may require a pick-list rather than free-text entry.^{29,30}

Aligning Patient and Clinician Expectations

Once all health care providers are using EHRs, the notorious "clipboard" where patients record, yet again, their demographic and medical history should disappear. Today, patients may resent having to repeat information multiple times, but consider it a necessary evil. Assuring patients that their doctor will have all their information is one of the

approaches to marketing EHRs to patients. In addition, personal health records (PHRs), in which patients will also have access to their health information and can record other information that they deem important are also possible.³¹ However, such promotion also raises patients' expectations that their physician or nurse will have thoroughly studied that information, which may not always be the case.

Differences between physicians and patients on what information is essential to their care may need clarification and mutual agreement. While elderly patients may be thrilled that now their current health care provider has access to their long medical history, the clinician may prefer access to a summary of pertinent data. A physician who is now very positive toward electronic personal health records for patients remarked how, as a resident years ago, he used to dread the patients who came with lengthy lists of all their symptoms expecting the physician to read it all. If we are successful with promoting EHRs and PHRs, clinicians' available time may not increase, but the amount of patient information will be more plentiful. For these reasons, as we set up these systems, we should anticipate the need for patient education and clarification of what information is necessary and wanted by the clinician and the patient.

Conclusion

All the issues raised in this article revolve around the need to develop tools and guidelines to enhance data accuracy and to enable filtering of the information that EHRs will make accessible to patients and health professionals. Medical informaticians have been at the forefront of developing the EHRs and decision support tools that are currently starting to be implemented in practice. We need to prepare now for the next decade and develop tools to filter and customize the information so that, rather than overwhelming the clinician with information, these systems can finally realize their potential to transform health care.

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