A PERFECT STORM is the convergence of factors that result in an unanticipated and very serious situation. Health data may be heading for one.

The migration to electronic health records (especially those that merge data from different sources), the emergence of a patient health data rights movement, and the continued lack of standardization in healthcare data and documentation are converging toward what some believe will be a perfect storm of consumer requests, complaints, and disputes involving the accuracy and quality of their personal health information.

It seems clear that electronic record systems will need to provide a means of communication and negotiation between consumers and providers when issues arise regarding the quality of health information. Such means will also help improve data quality and assist covered entities in complying with HIPAA regulations that grant consumers the right to amend their health information.

[Authors, above: are only providers affected here? Can payers and other healthcare entities expect an increase in questions and requests?]

A Convergence of Forces

Previously, the inconvenience associated with accessing paper-based health records from a variety of fragmented sources has left patients typically unaware of what information was contained in their medical records, let alone its accuracy or completeness. Even after the implementation of the HIPAA privacy rule—in which individuals were granted the legal right to receive copies and challenge the accuracy of their health records—the frequency with which most HIM professionals received such requests ranged from rare to never. However, as patients begin to gain access to the information in their providers’ electronic health records (EHRs) or collect and manage their own personal health records (PHRs) through online sources such as Google Health or Microsoft Health Vault, this is likely to change.

Public and private initiatives are also furthering the change. Patient access to personal health information is a recognized part of the effort to improve health outcomes, and it is a criteria for the “meaningful use” of health IT as defined in incentive programs in the American Reinvestment and Recovery Act. Patient access is regarded as allowing patients to become more active participants in their own healthcare, which can lead to the desired outcome of higher quality and lower cost.

The rise of social networking and environments such as Health 2.0 reflect important trends that are enabling and encouraging patients to take control of their health. Assuming greater control of their health inevitably also involves also taking greater control of their health information. This is reflected in blog posts that tell the stories of patients who challenge the accuracy of their personal health data as well as Web sites that inform and advocate for health information rights, including rights of ownership.

[Authors, above: would “information ownership” be more appropriate?]}

While control of personal health information implies the ability to access it, obtain copies of it, disclose it, and keep it private,
The Role of Health Literacy

ALTHOUGH SYSTEMIC ISSUES alone could cause increases in requests, complaints, and disputes from individuals, health literacy is another potential factor. Health literacy is more than the ability to read; it involves the capacity of individuals “to obtain, process and understand basic health information and services needed to make appropriate health decisions.” Nearly half of the US adult population is judged to have low functional health literacy.

Questions about the meaning of their personal health information, whether or not they involve the allegation of error, have traditionally been routed directly to the responsible healthcare provider. EHRs and PHRs with the capability to provide patient education materials as well as help patients submit questions to their providers could help to improve understanding and avoid potential disputes.

Notes

less attention has been paid to the ability to amend or correct information that the individual believes is inaccurate, misleading, or incomplete. This ability is critical not only for the obvious reason of patient safety, but also for the credibility and trust that patients place in their healthcare providers. Further, it is a right by law. HIPAA established a patient’s right to access his or her personal health information request amendments to it.

An important role for those developing and implementing EHRs and PHRs is to anticipate the perfect storm and plan accordingly. Planning will need to include well-defined operational policies as well as technological solutions that can provide efficient response to inquiries, complaints, and disputes.

All involved in this planning will need a solid understanding of the underlying causes of data quality issues in health records. Health information managers will play an important role in helping design solutions and processes that earn consumer trust by ensuring that concerns, questions, complaints, and even disputes are appropriately addressed.

Understanding the Opportunities for Error

Due to the great variability among systems and data types, little data exist regarding accuracy of information and data in EHRs. In general, however, data accuracy has to do with timeliness, relevancy, representation, and accessibility, and it involves both the content and the usability of information.

[Authors, above: the citation is to a 1997 article. Is this information still current, or can we point to more recent information?]

Both systematic errors (such as those in programming or data definition) as well as random errors (such as those in keying and transcription or system failures) contribute to the problem and make it more complex than merely providing the “right” information. Systematic errors seem to be prevalent and are the most difficult to address. The wrong data associated with a specific patient or the inability to obtain complete information for one patient because of multiple patient ID numbers are examples of systematic errors caused by lack of a standard for a unique patient identifier.

The complexity of the healthcare delivery system itself can contribute to problems related to the completeness and timeliness of health information. One study found that information regarding routine health maintenance procedures was frequently incomplete in the EHR when compared with patient report—largely because patients had obtained the procedures elsewhere. Another study found that medication lists were frequently inaccurate and most frequently excluded over-the-counter and nonprescription drugs.

Another type of error can be introduced by the data capture methods used in the EHR itself. Structured data entry that requires the user to make selections to capture data (e.g., pick lists and checkboxes) does not always allow the user to describe the specifics of individual patients and their conditions. For example, structured data may be inadequate to present a valid picture of individualized medical history, examination findings, differential diagnosis with patient-specific descriptions of severity or probability, and conditions affecting treatment options.

Errors in diagnosis and procedure coding are yet another source of data inaccuracy. An analysis of Medicare data found that 2.7% of nearly 11.9 million records, or approximately 321,300 records, contained coding errors, defined in the study as violations of coding rules.

[Authors, above: (1) clarification was added for what constituted error in the study, to distinguish from whether the coding accurately represented the actual condition of the patient or the care received. OK? (2) Data in the study are from 1997-98. Do you feel it is still reflective of coding quality today?]

There is also the perception of error and inaccuracy of coded data by patients due to the use of the ICD-9-CM coding systems for reimbursement, a purpose for which it was never intended. As a classification system, ICD-9-CM frequently does not contain the specificity necessary to describe conditions and services in information that would populate a patient’s personal health record—not such an uncommon use of this administrative health data today.

[Authors, above: is there also a chance for patient misunderstanding because codes may reflect the services provided rather than the final diagnosis (e.g., treated for AMI, but not necessarily diagnosed with it)?]

So while there is little understanding of the frequency of data errors in EHRs, the issues listed above are known to be common sources of error. Despite this, it is important to note that patients with access to their EHRs show a high degree of satisfaction with the use, completeness, and accuracy of the information contained therein. It will be important to maintain this satisfaction as electronic health information becomes more prevalent.
Resolving Disputes—Lessons from Others
All online environments that have generated large numbers of transactions, fostered many new relationships, and processed large amounts of data have needed to address the issue of disputed information. Other industries have learned that disputes involving personal information online can usually be resolved online.

There has also been a recognition that institutions benefit by assisting parties who are engaged in a dispute. eBay, for example, knew that it could, if it wished, ignore the disputes that arose between the buyers and sellers on its site. Instead, it decided to facilitate a dispute resolution process and, in doing so, found that dispute resolution was good for business.

Rather than allow many angry and frustrated buyers and sellers, eBay provides software to help the parties communicate with each other, identify possible solutions, and ultimately agree on a solution. In this manner, eBay handled more than forty million disputes in the past year.

Credit bureaus also provide efficient and easy to use applications for those who believe that there are errors in their credit reports. Unlike eBay, however, the systems now in place were not instituted voluntarily; they were required by the Fair Credit Reporting Act. Credit bureaus now provide on their home pages clear information about the rights of users and clear links to forms for filing claims.

It will be interesting to see whether, as EHRs and PHRs proliferate, online applications to facilitate resolution of disputed information will be instituted voluntarily, as eBay did, or will require more coercive action, as happened with the credit bureaus.

Although the government did not require the credit bureaus to provide online problem resolution, the bureaus soon discovered that this was the most efficient way to do so. Currently, few if any EHR or PHR systems provide resolution processes with the ease of access or use of those found at eBay or the credit bureaus.

Section 164.526 of the HIPAA security and privacy regulations provides 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.” Further, the covered entities must honor the individual’s request unless the information:

- Was not created by the covered entity
- Is not part of the designated record set; that is, was not used to make decisions about the individual
- Is not required to be accessible to the individual as listed in section 164.524 (a)(1), such as psychotherapy notes or information involving criminal actions
- Is accurate and complete

In paper-based records, this is clear: in the absence of these conditions, one can have a statement inserted in one’s health record stating that information is being disputed. It is fairly easy to exercise the right to request amendment. What is relatively difficult or inconvenient in the paper context is accessing the record and finding out what is actually in it.

With electronic medical records, access is easier but taking advantage of the right to request an amendment is more difficult. Who does the individual go to, particularly for a record where data have come from many sources? How does communication take place when the software used for the electronic record provides no capability for indicating that something is amiss in the record? Is a statutory right to request amendment sufficient even though figuring out how to ask for something to be amended is extremely difficult?

One of the oldest maxims of law is that “there is no right without a remedy.” In the case of EHRs, it is clear that there is a right but, to date at least, no efficient means to obtain a meaningful remedy.

Designing Systems That Facilitate Resolutions
Online dispute resolution such as that offered by eBay grew out of an earlier movement called alternative dispute resolution, which promotes methods for settling cases out of court. There are various forms of alternative dispute resolution, all of which are, in general, quicker, cheaper, less formal, and more flexible than litigation.

The three most common forms are negotiation, mediation, and arbitration. Negotiation involves the two parties alone. Mediation adds a third party who can help the parties but not impose a decision; arbitration authorizes a third party to make a decision that is binding.

Online dispute resolution software may be able to help healthcare entities expedite the negotiation process by facilitating requests for and communication regarding amendments or addenda. The functionality could help avoid the need for mediation, arbitration, and ultimately litigation.

EHRs and PHRs should incorporate system functionality that (1) helps consumers understand the informational content of what they are seeing, thereby addressing health literacy (see sidebar); and (2) captures information necessary to communicate requests to address disputed information and requests for amendment or addendum.

Consumer tools may include FAQs that provide general explanations of health information, glossaries that explain medical terminology, educational materials specific to diseases or procedures, and a method to communicate requests for changes to what is perceived to be inaccurate or incomplete health infor-

Desired System Functions
- Glossary of common health terms
- FAQs about health information content
- Access or links to patient education materials
- Communication functionality to report errors and request changes
- Workflow automation to route requests to responsible party, track response times against compliance requirements, indicate status of request, resolution and re-distribution of corrected information, as appropriate
Online forms that collect information about the nature and type of the disputed information should be clear and concise, and they should clearly and directly state that the form is not intended for medical care issues or communication with a physician.

As clear as these warnings may seem to health professionals, consumers can easily misunderstand them. Therefore, their design and implementation require the insights and input of a variety of stakeholders, such as members of the clinical team, patient advocacy and education, IT, and HIM.

Using workflow automation or other tools, EHRs and PHRs should also facilitate the receipt and processing of consumer requests for changes in health information. Such tools can assist with screening the request against the HIPAA criteria and routing the request to the appropriate party for review and action.

For instance, in a hospital or large clinic, the HIM department would typically perform initial screening, where changes due to clerical errors such as electronically misfiled information or misspelled name could be made by personnel. However, any substantive content changes to the clinical information would need to be routed to the responsible physician or clinician for a decision and updating of the information as appropriate.

The system could also keep track of compliance time frames and responses to and communication back from the consumer. It could potentially facilitate sending updates to those who may have previously received erroneous or incomplete information.

If properly addressed, the convergence of the factors in the perfect storm will ultimately result in a higher level of data quality in electronic health records rather than disputes and dissatisfaction.

Notes

[Authors, below: several notes were omitted because they were not considered core citations. The remaining notes are not renumbered in this proof, so you can see which notes were omitted. (The notes will be renumbered after this proof.)]


8. [should be 7?]. AHIMA. “Quality Data and Documentation for EHRs in Physician Practice.” *Journal of AHIMA* 79, no.