EXECUTIVE SUMMARY

Demonstrating the Effectiveness of Patient Feedback in Improving the Accuracy of Medical Records

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Executive Summary

NORC at the University of Chicago (NORC) is pleased to present this final report on, "Demonstrating the Effectiveness of Patient Feedback in Improving in the Accuracy of Medical Records" to the Office of the National Coordinator for Health Information Technology (ONC). ONC's Office of Policy and Planning (OPP) contracted with NORC to conduct an assessment on the role of patients in improving the accuracy of information in their medical records. Providing patients with opportunities to give feedback rightly acknowledges that patient-generated information can enhance the accuracy and completeness of the medical record.

This project focused on data quality improvements that are likely to result from increased patient access to electronic health records (EHRs) and it explored solutions currently pursued by leaders in healthcare and other industries. Data quality is an umbrella term that encompasses accuracy, timeliness, accessibility, and clarity of presentation.¹ Phase 1 of the study examined the current state of the field, specifically the experience of healthcare organizations and approaches they are taking to encourage and process patient feedback. Phase 2 involved a pilot study at Geisinger Health System where patients were encouraged to provide feedback on their medication list within their EHR, in advance of patient visits. This final report demonstrates that patients can be effectively engaged online to improve the quality of the information stored in their EHRs. We hope that findings from the report will provide valuable insights to policy makers, researchers and the healthcare community on the important role of patient feedback to the medical record and how institutions can effectively gather and process this information with the ultimate goal of improving safety and the quality of treatment.

Background

With the widespread adoption of EHRs and advancement in health information exchange, providers will more readily exchange medical information about their patients with other providers, and patients will have more opportunities to engage with clinical teams about their medical records. While the goal of these interactions is to improve continuity of care and patient safety, the NORC 2010 environmental scan found patients with access to their medical information are likely to have questions, identify inaccuracies, or have information that may impact the data in their health records.

The research literature contains numerous studies documenting themes related to data quality that patient inspection and feedback could successfully address although the diversity of the studies makes direct comparison challenging. For example, a recent review of data quality studies² referenced two studies that

reported 81% and 95% errors in medication lists.^{3, 4} Separate studies noted medication omission rates of about 27 percent for ambulatory oncology patients⁵, and 53 percent for primary care patients.⁶ In the same literature review, authors reported that studies of medication lists show significant errors. Inaccurate information was present in 81 to 95 percent of patient records. Errors due to retention of discontinued medications were common while incorrect medication regimens were less common.

Findings from the environmental scan also revealed that patients and doctors believe it is important to check the correctness of information in the EHR. A 2010 California Healthcare Foundation survey found "making sure that information is correct" is the personal health record feature most commonly cited as useful.⁷ A 2010 Markle Foundation survey finds similar agreement between patients and providers on need for a correction process.⁸

To assess the current state of the field in the first phase of the project, we reviewed eight patient portals offered by integrated delivery systems. Not surprisingly, the attitudes and methods of patient engagement differed among the various patient portals and personal health record systems reviewed for the study. However, there were some clear preferences and healthcare organizations were generally requesting feedback on allergies, immunization data, and medications. There was significant variability in the approaches used to gather feedback and respond to queries. In most cases secure messaging or free text was used to gather patient feedback but in a few cases, for example Childrens Hospital Boston, NorthShore, University Health System and Kaiser Permanente, a focused form was also used. The backend processing that supports triage and routing messages varied considerably and ranged from a central triage desk manned by appropriate professionals to messages routed directly to providers.

For comparison, the environmental scan also considered industries outside of healthcare in which data quality is important. The most notable example of large-scale online problem-solving is the online auction site eBay. eBay's feedback rating system enables potential buyers to determine the reliability of a seller based on previous sales. When eBay began, the company refused to remove any contested feedback postings or to mediate differences of opinion between a buyer and a seller. The company soon realized, however, that it needed a process to adjudicate grievances and, if necessary, to remove feedback. eBay changed this practice after finding that resolving problems builds trust and acknowledging problems, rather than ignoring them, was better for business.

If EHR software does not allow users to report problems swiftly and easily, an accurate picture of care will not be available. Efficient communication of quality concerns can contribute to healthcare quality, improve care delivery, and build trust between patients and providers.

Overview of the Pilot Study

NORC partnered with Geisinger Health on a pilot study where patients were invited to provide feedback on their medication lists in advance of a scheduled doctor's visit. This project was initiated in November 2011, as part of a larger organizational initiative on medication reconciliation.

Overview of Geisinger. Geisinger Health System is a physician-led, not-for-profit, integrated delivery system that serves an area with approximately 2.6 million people in northeastern and central Pennsylvania. In 2002, Geisinger completed implementation of its outpatient EHR and uses the system across all of its group practice sites. At the time of the study 200,785 patients had active accounts on Geisinger's patient web portal, MyGeisinger, which they could use for health information, appointment scheduling, prescription ordering, checking lab results, e-mailing with clinicians, and to receive and act on clinical decision support.

Goals of the pilot. The pilot study had three goals: 1) Determine the interest of patients in becoming engaged to improve the accuracy of information in medical records; 2) Assess processes for obtaining and processing patient-generated feedback; and 3) Assess impact of the patient feedback.

MyGeisinger Pilot. The process for obtaining and processing online medication feedback can be summarized as follows:

- Patients were sent an electronic link to a medication feedback form, pre-populated with their current active medication list derived from their EHR record. Patients had the option of indicating which medication they were no longer taking, which they were taking differently from the way the instructions were presented, and which medication they were taking which were not listed.
- Patient responses were routed to a Geisinger pharmacist, who reviewed the patient's input, and attempted to follow up with the patient.
- Following the pharmacist review and possible patient contact, the pharmacist updated the medication record and notified the patient's physician and case manager (in cases where one has been assigned to the patient) about any changes by completing a note in the EHR.

Geisinger has been testing the process at two clinic sites. Inclusion criteria for the study target patients with specific chronic conditions (i.e., COPD, asthma, hypertension, diabetes or heart failure) who are active MyGeisinger users—patients who have logged in at least once and have at least one upcoming scheduled appointment with their primary care physician.

Methods

To study the intervention we used a mixed method approach. Qualitative activities included patient focus groups with three types of users: those who submitted a medication form, those who partially completed the form, and those who did not submit a medication feedback form. We also conducted user observations with patients that submitted the feedback form to gather additional perspectives from patients on the usability and usefulness of the form. Other qualitative activities included semi-structured discussions with the pharmacists and providers participating in the pilot study.

Quantitative methods included an analysis of four sets of data. 1) MyGeisinger usage data were obtained for all MyGeisinger users from January 2012 through June 2012 and for all patients who submitted completed medication feedback forms. 2) Demographic and health condition data, including age and sex, were obtained for the sample population (all patients that submitted a medication feedback form). 3) Medication feedback data (i.e., a count of the invitations sent and all completed responses) were obtained for the sample population.. 4) Pharmacist medication reconciliation logs for all patients who submitted a completed medication feedback form in response to invitations sent out in an eight-week period.

Key Findings

We gleaned many insights from the Geisinger pilot regarding how patients can be engaged to provide feedback, the workflow and processes that can support patient feedback, and the reliability of the information provided by patients. Below we summarize the most salient findings.

Patients are eager to provide feedback on their medication data and see numerous advantages. Analysis of the quantitative data showed, 30 percent (457 of 1500) of patient feedback forms were completed and submitted to Geisinger. In 89 percent of cases (369 of 414 forms received) patients requested changes to their medication record. These included changes to frequency and/or dosages of existing medications and requests for new medications to be added. Patients requested changes to dosages and/or frequencies in 281 of 369 forms. The 281 forms included a total of 661 requests for changes to medication entries, for an average of 2.4 requested changes per patient form. Patient focus group findings suggest that most patients find that online access to their medication lists and an opportunity to provide feedback allows them to track their medications more easily. Patient access also enhances communication with their providers and better prepares them for office visits. Together, this increased access and communication allows patients to take a more active role in managing their medications.

- Patients can provide useful and accurate information through online feedback systems. In reviewing pharmacist responses for a sample of 107 forms submitted, in 68 percent of cases the pharmacists made changes to the MyGeisinger medication list based on patient feedback. The analysis showed that pharmacists accepted 51 percent of medication updates requested by the patients even when they could not contact them by phone and 67 percent changes when they could contact them. Discussions with pharmacists involved in the study suggest they were 'impressed' at the accuracy of the information provided by patients given that, on average, patients have 10.7 medications listed.
- Processing patient feedback will require both software and human adjudication. For the Geisinger pilot, pharmacists reviewed all feedback received from patients. In reviewing the medication forms, pharmacists regularly communicated with patients (and in some cases other pharmacists) as they reconciled patient feedback with the existing EHR record. Findings from patient focus groups suggest that patients found these communications with pharmacists reassuring and wanted assurance their information was reviewed by a trusted health professional before any changes were made in the medical record. However, on a large scale, review of all patient feedback, by a healthcare professional, could be a time and resource intensive prospect. The 51 percent of medications pharmacists updated without contacting patients present opportunities to facilitate human processing. Therefore, while a human intermediary would be necessary in some cases, others could proceed without human intervention and there are opportunities to automate processing of certain types of medication feedback data.
- Acceptance of online patient feedback system is more likely to work if there is an existing supportive overall e-health/online health environment. Review of usage data provided by Geisinger showed that patients who completed the medication feedback form accessed MyGeisinger 2.3 times the average and initiated secure messages 1.35 times as often. In the focus groups, patients reported finding MyGeisinger useful and physicians were very responsive to patient online communication as providers often responded to secure messages within a couple of hours.

Software can facilitate the HIPAA goals of access and amendment. The HIPAA Privacy Rule provides individuals the right to examine and obtain a copy of one's health information and a right to request an amendment to information in the record. EHRs do not change these rights. They may provide easier and more effective ways for patients to exercise these rights and for providers to meet HIPAA requirements. Findings from the Geisinger pilot suggest an online portal combined with efficient and secure communications options will meet the needs of patients who might otherwise wish to exercise these rights. Medication reconciliation provides an opportunity for a patient to update some critical information in one's record and for collaboration between patients and providers, as opposed to a formal amendment request under HIPAA.

Conclusions

Findings from the Geisinger pilot demonstrate that patients can be effectively engaged online to improve the accuracy of the information stored in their EHRs. It has provided valuable insights into effective strategies to gather patient feedback, to organize the back-end workflow and processing of patient feedback and to provide an opportunity for EHRs to assist in maintaining accurate and complete medical records. Furthermore, the data shows that patients are eager to provide feedback and the information they provide is likely to result in more accurate and up-to-date information. In many ways online medication reconciliation provides a model for collaborative processes that can be employed to improve the quality of problem lists, immunizations, allergies and other areas of the medical record. The Geisinger pilot has highlighted a number of areas that would benefit from additional study. These include studies to optimize form elements for patient feedback in other areas of the medical record such as medications and allergies; methods to efficiently automate form processing, mapping the impact on physician office workflow; and assessing outcomes related to cost, patient quality, and safety.

In conclusion, we observed an example of how the goal of patient engagement was achieved seamlessly through patient/provider collaboration via the electronic health records.

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