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“POLICY ISSUES RELATED TO PATIENT REPORTED DATA”

**WRITTEN TESTIMONY OF PRASHILA DULLABH
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Thank you for the opportunity to testify today. I am Prashila Dullabh, Program Area Director for Health IT at NORC. I am the project director for an ONC-funded study assessing the role of patients in improving the quality of information in their medical records.

A key objective of the Federal Health IT Strategic Plan is to “accelerate individual and caregiver access to their electronic health information in a format they can use and reuse.”ⁱ These patient-engagement-focused objectives are critical in achieving the benefits of an electronic healthcare environment.

Giving patients access to their medical information is important for patient engagement but providing opportunities for patients to contribute to the content of their record is equally important. Providing these opportunities rightly acknowledges that patient-generated information can enhance the accuracy and completeness of the medical record.

As the Policy Committee considers whether and how to include allowance for Patient-Generated Data in the Meaningful Use requirements, we would like to make you aware of findings from an ONC-funded project that assesses the role of patients in improving the quality of information in their medical records. The project has two phases: Phase 1 explores the current state of the field, specifically, healthcare organizations and approaches they are taking to encourage and process patient feedback; and Phase 2 involves a pilot study at Geisinger Health System where patients are encouraged to provide feedback on their medication list in advance of their medical visits. This data is being analyzed using a mixed methods (qualitative and quantitative) approach and preliminary results suggest the favorability of including patient feedback to achieve accurate and complete medical records.

Overview of Geisinger

Geisinger Health System is a physician-led, not-for-profit, integrated delivery system offering innovative products and services designed to drive higher performance. Geisinger serves an area with approximately 2.6 million people in northeastern and central Pennsylvania. Geisinger’s annual patient volume exceeds 40,000 inpatient discharges and 2.4 million outpatient visits, and the system employs more than 900 physicians in 42 practice sites, all of which include primary care.

Geisinger completed implementation of its outpatient EHR in 2002 and uses the system across all of its group practice sites. The system, which also incorporates decision support, now contains more than 3 million patient records. More than 197,000 patients use Geisinger’s patient web portal, MyGeisinger, for health information, appointment scheduling, prescription ordering, checking lab results, e-mailing with clinicians, and to receive and act on clinical decision support.

MyGeisinger Pilot

In November 2011, Geisinger initiated a medication feedback pilot at two clinic sites (Berwick and Pottsville, Pennsylvania) as part of its broader medication reconciliation effort. 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 scheduled upcoming appointment with their primary care physician. Key steps for the pilot include:

- Patients are sent an electronic link to a medication feedback form, pre-populated with their current active medication list from their EHR record. They are asked to review the medication list prior to their doctor's visit and electronically submit changes in frequency and dosage, new or discontinued medications, and any questions about their medications.
- Patient responses are routed to a Geisinger pharmacist, who reviews the patient's input, and follows up with the patient, if necessary, either via a phone call or through a secure message using MyGeisinger.
- Following the pharmacist review and possible patient contact, the pharmacist updates the medication record and notifies the patient's physician or case manager (in cases where one has been assigned to the patient) about any changes by completing a note in the EHR.

Key Findings

The NORC team used a mixed method approach to analyze the intervention. Qualitative methods included informant discussions with key project staff and patient focus groups. Quantitative methods included analysis of patient-submitted data and a review of pharmacy medication reconciliation logs. Data collection continues and initial analyses are underway. Preliminary findings indicate:

- **Patients are eager to provide feedback on their medication data and see numerous advantages.** Between November 2011 and April 16, 2012, 866 medication feedback forms were sent to patients. Of these, 35 percent of forms (302 of 866) were completed and another 16 percent of forms (141 of 866) were partially completed. 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 in that it better prepares them for office visits. Taken 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.** An analysis of 139 patient feedback forms revealed that 252 medications were changed by the pharmacists based on patient-generated data. Of these changes, pharmacists deleted 226 medications, added 19 medications and updated medication frequency or dosages in 7 cases. An additional 142 forms are being reviewed. Anecdotal information shared by pharmacists involved in the study suggests that they implemented patient requests for changes in more than 80 percent of cases. In discussion groups, providers at the pilot sites indicated that when patients are able to review and provide feedback on their medication lists online, medication reconciliation is more efficient during in-person medical visits. One provider reported spending half the usual amount of time on medication reconciliation, a huge time savings given doctors often have only 15 minutes per patient. Data collection and quantitative data analysis continues. Results should be available in 60 days.

- **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 providers) as they reconciled patient feedback with the existing EHR record. Findings from patient focus groups suggest that patients found these communications with pharmacists reassuring. They were pleased that the feedback they provided was adjudicated by a trusted health professional before any changes were made in the medical record. However, on a large scale, human adjudication could be a time and resource intensive prospect. Findings from discussions with pharmacists suggest there are opportunities to employ decision support rules within the EHR to automate the processing of certain types of medication feedback without pharmacist intervention. Therefore, while a human intermediary would be necessary in some cases, others could proceed without human intervention. In the next phase of the study, Geisinger will assess the feasibility of implementing decision support rules to create efficiencies in the medication feedback process that will allow them to process larger numbers of patient requests for changes.
- **Acceptance of online patient feedback system is more likely to work because of an existing supportive overall e-health/online health environment.** Findings from the Geisinger pilot suggest that for the patient feedback process to work, an environment that supports and leverages online consumer interaction is necessary. Usage data from the two pilot sites indicates that, on average, 30 percent of patients at each site are active users of MyGeisinger (consistent with overall Geisinger use rates). In the focus groups, most patients expressed satisfaction with using MyGeisinger to perform various convenience functions like scheduling appointments, requesting refill prescriptions, reviewing test results, tracking medications, learning about procedures/tests, and sending secure messages to physicians. Patients also reported finding online interactions meaningful, as Geisinger is very responsive to patient online communication; providers often respond to secure messages within a couple of hours, and use the portal to send preventive health and appointment reminders and to communicate other relevant information to the patient about their health.

Responses to Questions from the Policy Committee

Incorporation into the legal medical record: How does the provider "review and accept" patient-entered data into the medical record?

In the first part of the project, the NORC research team completed a review of feedback processes in patient portals offered by eight integrated delivery systems.ⁱⁱ The NORC team looked at the different portals and different types of health data and categorized the feedback mechanisms as either *encouraging* or *facilitating* feedback. *Encouraging feedback* involves text on the page that acknowledges the potential for issues and recommends that a patient contact their provider. *Facilitating* feedback takes the additional step of providing online mechanisms to accept patient input, essentially providing a "Feedback Button." In five of the eight portals medication list feedback is either encouraged or facilitated. Facilitation is most commonly available for updates to medication lists, allergies and immunizations. This and other results of the Phase 1 study are covered in more detail later in the testimony.

Although some organizations send patient feedback directly to the appropriate physician, most establish a triage function where a nurse, pharmacist or medical records professional reviews the

input first. They consult other records or organizations and, if necessary, contact the patient for clarification. They can then incorporate or reject the patient's input to the record and alert the physician, or they can pass the patient's input directly to the physician. Triage appears to support more efficient and effective processing of feedback. It also suggests that new roles may emerge as electronic communications becomes a routine route for patients to collaborate with providers to maintain accurate records.

Incorporation into the legal medical record: What are the responsibilities for review of (and appropriate action on) patient data that feeds into the EHR?

For patient-generated data to be included in the medical record, a process of adjudication or evaluation of the content is necessary. One approach could involve a combination of electronic means, such as decision-support algorithms embedded in software, and human adjudication.

Findings from the Geisinger pilot and the NORC environmental scan demonstrate that clinical context should drive assignment of human-led responsibilities for review of and appropriate action on patient data. In the Geisinger pilot, where patients provide feedback on their medication lists, a pharmacist conducted the review of patient-generated data. However, another trusted health professional such as a registered nurse, case manager, physician assistant, or physician could also complete this review. In other situations, health information department staff may be better suited to process feedback on content of the medical record.

Future pilots focusing on different aspects of the medical record are necessary to generate more evidence on best practices for processing and incorporating patient generated data for larger numbers of patients.

Information reconciliation and amendments to the medical record: How do we indicate patient source of information?

From the eight portals reviewed, Children's Hospital Boston provides the most extensive support for patient feedback. MyChildren's portal combines a patient portal integrated with the hospital EHR with the Indivio personally controlled health record. Patients view data from the hospital's health record and can add or edit most types of information. MyChildren's portal keeps the patient-entered data separate from the hospital's EHR data. Patients and providers view a combined record marked with the source. In this case, the system does not modify patient-entered data in any way but users of the record see all data and its sources.

In the Geisinger pilot, currently, patient-generated data does not persist in the EHR but is held in a separate database. For the next phase of the study, Geisinger is assessing how information provided by patients, via the patient feedback form, will be stored within the EHR. This could allow the EHR to automatically generate metadata; which would link pharmacists encounter notes to stored patient input.

It seems likely processes will differ, depending on how information integrates into the medical record. In the case of the MyChildren's portal, patient-generated data was unaltered and clearly marked as patient-provided. In the Geisinger pilot, where patient-generated data is 'adjudicated' and resulted in a change in the medical record, all the pharmacists actions relating to the review of the medication record and subsequent actions were recorded and stored as part of the permanent medical record.

Information reconciliation and amendments to the medical record: What is the process for amending/accepting and/or commenting on submitted information?

The Geisinger pilot suggests a need to be cognizant of the various kinds of information that will lead to interactions between patients and providers. We view medication reconciliation as more of an updating process than an amending one; more of a collaboration between patients and providers than a formal amendment request under HIPAA. In the medication reconciliation process, it is probably fair to say that the request for information and the use of a process for making changes originates with the provider. We also consider it likely that informal requests for corrections will, as is the case with paper files, outnumber formal amendment requests.

This does not mean that there is any less need for a process for verifying and authenticating patient input. We do, however, anticipate that frequent or recurrent types of requests can be modeled and that forms can be developed for efficiently facilitating changes. What this means is that, in addition to rules and regulations, processes are necessary to encourage patient contributions in a manner that satisfies the data quality concerns of providers and others who are responsible for the records.

Members of the NORC team have experience advising on processes for updating and correcting systems in which electronic records are maintained. While the medical context has certain unique features and demands, our experience in non-medical contexts can provide guidance on how to value patient contributions to medical records. Entities that have developed procedures for responding to user queries include financial institutions such as credit bureaus, credit card issuers and banks, firms that supply information about work histories, and e-commerce and other online sites that create reputations potential users of a site consider before making a purchase or using a service. Some of these are guided bylaws that, like HIPAA, mandate consumer access to one's record. Others simply allow access in the absence of legislation, having determined that consumers participate in improving the data quality of the records and that building trust in any enterprise requires the correction of errors. The challenge of understanding the provenance of user-submitted information, in other words, is an issue in medical and non-medical contexts, but a challenge worth engaging in given the trust and data quality that results from user input.

Key Findings from the Environmental Scan

Phase 1 of the NORC project explored the current approaches taken by healthcare organizations to encourage and process patient feedback. In the sections below, we include some salient findings relevant to the discussion on patient-generated data.

Medical Records and Considerations for Data Quality. According to survey results, patients and doctors believe it is important to check the correctness of electronic medical records. A California Healthcare Foundation survey found that “making sure that information is correct” is the personal health record feature most commonly cited as useful.ⁱⁱⁱ A Markle Foundation survey finds similar agreement between patients and providers on need for a correction process.^{iv}

The research literature contains numerous studies documenting data quality issues that patient inspection and feedback could successfully address although the diversity in the studies makes direct comparison challenging. For example, a recent review of studies of data quality reported medication lists omission rates of between 27 percent of patients for ambulatory oncology patients^v and 53 percent for primary care patients.^{vi} 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.^{vii} Errors because of retention of discontinued medications were common while incorrect medication regimens were less common.^{viii} Standard reconciliation practice includes asking what medications a patient is taking, about allergies, as well as, symptoms. Organizations are using patient portals to gather patient feedback and/or correct medications and other types of data.^{ix}

Findings from the Review of Eight Patient Portals. Table 1 shows the penetration of patient feedback mechanisms by health data type in the 8 patient portals surveyed in late 2010.

Table 1: Survey of eight patient portals

Health Data	Available Online	Encourage Feedback	Facilitate Feedback
Medications	8	2	3
Allergies	7	1	4
Immunizations	6	1	3
Laboratory Results	7	1	1
Problem Lists and Diagnosis	6	1	1
Vital Signs	5	1	1
Clinical Summary and Discharge Instructions	6	1	0
Radiology Results	5	0	1
Medical History	5	1	0
Clinical Notes	0	0	0

In order to understand the shortcomings in current practice, we also conducted interviews with patient advocates, EHR vendors, privacy officers, integrated delivery systems and organizations representing ambulatory providers and medical records professionals. These interviews helped us develop an understanding of the barriers to more general acceptance of patient feedback, which are similar in many ways to barriers facing online communication (Table 2). Particular issues that must be addressed include concerns over the process for establishing correct facts (reconciling discrepancies between patient feedback and the medical record), the difficulty of correcting errors (including propagating the corrections to all relevant records), liability concerns, and the technical limitations of EHR systems (e.g., the inability of EHR systems to record patient generated data).

Table 2. Barriers to expanded support for patient feedback on data quality from 17 interviews

Category	Instances
Provider workload and time demands	10
Provider difficulty of establishing correct content	6
Inappropriate use of online mechanisms by patients	5
Provider difficulty of correcting errors	5
Provider lack of guidance on appropriate practices	5
Lack of provider reimbursement	4

Category	Instances
Provider liability concerns	3
Patient awareness of their ability to provide input	3
Technical limitations of EHR systems	2
Confidentiality and security liability concerns	1

Examples from Outside of Healthcare. The environmental scan also considered industries outside of healthcare in which data quality is a significant concern. 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, it refused to remove any contested feedback postings or to get involved in any differences of opinion between a buyer and a seller. It 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 that acknowledging and resolving problems was better for business than ignoring them. For example, eBay found that when they denied a party's claim quickly, that party was more likely to conduct future business on eBay than parties who won in a lengthy process. Moreover, eBay discovered that if supported effectively by software, resolution of disputes did not require human adjudication in the majority of cases. Figure 1 shows one example form from a Paypal dispute resolution process. Taking into account both eBay and its PayPal subsidiary, eBay resolved over 60 million disputes in 2011 with approximately 90 percent of disputes handled through software.

Figure 1. Example PayPal Dispute Resolution Form

PayPal

My Account | Send Money | Request Money | Merchant Services | Auction Tools | Products & Services

Not as described - Claim - #PP-001-011-237

Status

Your buyer has reported a problem with this transaction and we have opened an investigation into this transaction. Please respond to this claim by **Aug. 3, 2008**.

Transaction
#6P651821MV395264B

\$5.00 USD
Jul. 24, 2008

James Moore
lvenkit-nht1@paypal.com

eBay Item(s):
[#2926937232](#)

Shipping address:
James Moore
196736 Hillside Court
Santa Monica, CA 90401
United States

How would you like to respond?

- Issue the buyer a full refund.
- Provide the buyer a full refund if the package is returned.
- Offer the buyer a partial refund in an attempt to close this claim.
- Provide proof that the buyer has already been refunded.
- Disagree with claim. I would like to provide additional information.

[Continue](#)

Another interesting phenomenon that eBay observed was that the number of problems reported varied based on the number of mouse clicks required to report that problem. The more mouse clicks required, the fewer problems users reported. In the EHR context, this suggests that if EHR software

does not allow users to report problems swiftly and easily, an accurate picture of care will not be available. Facilitating this ease may be a matter of both minimizing mouse clicks as well as providing guides, tools and resources for making corrections. Efficient communication of quality concerns can not only contribute to the overall picture of health care quality but, in many cases, reduce the need for office visits for which the purpose is to clarify unclear or misunderstood information.

Checklist for Patient Feedback

Based on our study of other industries and a review of healthcare quality initiatives, we have identified key areas of consideration for organizations transitioning towards accepting online patient feedback for data quality purposes (Table 3).

Table 3. Key considerations for patient feedback on data quality

Patient-facing Needs	Provider-facing Needs
Modifications to the portal user agreement	Policy statements
Methods to make patients aware	Processes for reconciling patient input
Online explanation of purpose & processes	Tools and systems for managing responses
Screens for each type of the HR information	Methods for storing patient input
	Methods for propagating corrections
	Continuous improvement systems
	Implementation handbook and staff training manual

In most cases, organizations need to develop these materials and tailor them to their specific organizational and user needs. Findings from the study suggest it is time to facilitate the collection of online patient feedback to improve data quality.

Study Limitations

- The environmental scan included a review of patient portals from eight large integrated delivery systems. We were not able to identify any similar initiatives in ambulatory practices not part of large delivery systems.
- Findings from the medication feedback study are from one institution only. While we recognize this limitation, we note Geisinger was the only organization identified that was studying the use of a patient-feedback form for medication lists.

Key Conclusions

In summary, findings from the NORC research indicates that there is value in patient generated data and that progress is being made on how to manage, process and integrate this information into the medical record.

- Patients are eager to provide feedback and can provide useful and accurate information through an online feedback mechanism.

- Processes for provider review and acceptance of patient-entered data will vary. Our research shows while some organizations sent patient feedback directly to the doctors' office, most have established a triage function where an appropriate individual such as a nurse, pharmacist or medical records professional reviews the input. Processing may involve both software and human intervention. We realize not all of these processes can be completely automated, but there are efficiencies to be gained from some automation.
- Findings from the research project shows there may be different ways in which patient-generated data is integrated into the clinical record and the clinical context is likely to influence this. In the case of MyChildren's patient-generated data is clearly marked and displayed alongside provider-generated content. In the Geisinger pilot, all patient feedback is reviewed by pharmacists and these actions are stored as part of the permanent medical record.
- Findings from the Geisinger pilot suggest for the patient feedback process to work, an environment that supports and leverages online patient/provider interaction is necessary.
- Future pilots focusing on different aspects of the medical record are necessary to generate more evidence on best practices for processing and incorporating patient generated data for larger numbers of patients.

At the heart of any data improvement or problem solving process is communication. Our experience with Geisinger illustrated that providing opportunities for communication is a necessary but not sufficient first step. Geisinger recognized processes for communicating must be accompanied by attention given to ease of use, accessibility and processes for encouraging patients to use the system.

As more patients become familiar with their EHRs and as use of new communications tools accelerates, problems and concerns associated with their records will inevitably be noticed. Interactions between patients and providers will increase and not all such interactions will be frictionless. A few of the many possible sources of such problems and the factors affecting them include unintended miscommunications, unfamiliar and complex software, and changes in roles and relationships. Findings from the research study suggests a well-structured online environment and a cooperative and conscientious community of healthcare providers who utilize it for effective communication can potentially lead to better data quality within the EHR.

NORC welcomes your feedback on this important topic and is happy to share additional materials with the HIT Policy Committee and ONC, as it evaluates requirements for subsequent phases of Meaningful Use. Thank you again for the opportunity to testify on the importance of patient-generated data.

ⁱ Office of the National Coordinator for Health Information Technology. Federal Health Information Technology Strategic Plan 2011-2015. [Online]. 2011. [Cited 2011 August 15] Available from: <http://healthit.hhs.gov/StrategicPlan>

ⁱⁱ Beth Israel Deaconess Medical Center, Children's Hospital Boston, Geisinger Health System, Kaiser Permanente, NorthShore University Health System, Palo Alto Medical Foundation, Partners HealthCare, Veterans Health Administration

ⁱⁱⁱ Consumers and Health Information Technology: A National Survey, April 2010

^{iv} Markle Survey on Health in a Networked Life 2010

^v Weingart, S. N., Cleary, A., Seger, A., Eng, T. K., Saadeh, M., Gross, A., et al. (2007). Medication reconciliation in ambulatory oncology. *Joint Commission Journal on Quality and*

Patient Safety, 33, 750-757.

^{vi} Varkey, P., Cunningham, J., & Bisping, D. S. (2007). Improving medication reconciliation in the outpatient setting. *Joint Commission Journal on Quality and Patient Safety*, 33, 286-292.

^{vii} Chan KS, Fowles JB, Weiner JP. Electronic health records and reliability and validity of quality measures: A review of the literature. *Med Care Res Rev*, Feb 11, 2010

^{viii} *Ibid.*

^{ix} Katsh, E., Sondheimer, N., Dullabh, P., and Stromberg, S. Is There an App for That? Electronic Health Records (EHRs) and a New Environment of Conflict Prevention and Resolution, *Law and Contemporary Problems*.