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Subcommittee on Privacy, Confidentiality, and Security
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TESTIMONY BY THE AMERICAN MEDICAL ASSOCIATION

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The American Medical Association (AMA) would like to thank the National Committee on Vital and Health Statistics' (NCVHS) Privacy, Confidentiality, and Security Subcommittee (Subcommittee) for the opportunity to provide physicians' views on personal health records (PHRs). The AMA supports strong and effective patient-physician communication, and we support the meaningful use of PHRs to improve patient care and health outcomes. We believe in the promise of electronic interfaces, including PHRs, to improve and facilitate clinical interactions between patients and physicians. Effective PHRs will help link patients and physicians and will be useful to both in their work as partners. Patients with untethered PHRs (those not tied to physician EHR systems) should discuss them with their physicians, including their expectations for how they hope to use them to improve their care.

The AMA has long made sure that the confidentiality and security of patient medical information remains a top priority. Meaningful enforcement mechanisms and remedies must be in place to protect health information contained in PHRs from inappropriate use and disclosure. In 2008, the AMA and the Markle Foundation surveyed physicians and patients on the use of PHRs. Today, I will provide you with a summary of the views of physicians on several key issues surveyed, ranging from the varying uses, interoperability issues, risks and costs of PHRs to concerns over the privacy, security and reliability of patient health information contained in PHRs. These survey results represent a snapshot in time. Physicians realize that electronic systems and tools, including PHRs, will continue to evolve and improve over time and are open to new technologies that will enhance shared clinical decision making and communication between physicians and their patients. Where the survey results demonstrate physicians' concerns, these findings can help shape the evolutionary process for PHRs so that they will serve as a vital link in quality health care.

Physicians' Views on PHRs

PHRs are evolving and they should be distinguished from electronic health records (EHRs). The recently enacted "American Recovery and Reinvestment Act of 2009" (ARRA) defines a PHR as an electronic record of identifiable health information on an individual that can be drawn from multiple sources and that is managed, shared, and controlled by or primarily for the individual. ARRA also defines an EHR as an electronic record of health-related information on an individual that is created, gathered, managed, and consulted by authorized health care clinicians and staff.

Physician views on PHRs are often positive, but nuanced, demonstrating awareness that PHRs might bear some risks as well as benefits. In a set of surveys of patients and doctors that the AMA and the Markle Foundation conducted in 2008, a large majority of those patients who had used a PHR felt they were valuable, but very few had used them and just under half said they would be interested in trying to do so. The physician survey data are preliminary and as yet unpublished, but among physicians about half thought PHRs could empower patients to participate in their care and just under half said they would be willing to use PHRs in their clinical work. Fewer than one quarter, however, agreed that using PHRs would improve their relations with patients (one-third disagreed) and only about a third agreed with the general statement that PHRs would “improve the quality of care.” Meanwhile, large majorities worried that PHRs might contain incorrect information, that privacy protections were not adequate, and that patients might omit important information from their PHR.

These mixed views might simply reflect a wait-and-see attitude towards PHRs, which are a technological tool that few patients or doctors have any experience using as yet. In May of 2006, 52 percent of consumer respondents to one survey said they had never used a PHR product because they had never heard of one. Among patients in 2008, fewer than 3 percent had an electronic PHR. Among physicians in 2008, almost 20 percent had seen some kind of PHR, but two-thirds had never used one.

These mixed views and low adoption rates of PHRs among patients and physicians might also reflect some underlying fears of this type of tool and its potential for unintended effects. But they should not be interpreted as reflecting an unwillingness of patients or physicians to use technology. In fact, patients and doctors often use technological tools to accomplish specific, high-value tasks. Many physicians use some electronic records (in our survey, almost half used some electronic records in their primary practice and almost 70 percent at the main hospital where they admit patients), though very few have converted to all-electronic records. Nationwide, more than 75 percent of claims, and 95 percent of Medicare claims for Part B, are now submitted electronically. Most patients like using email to communicate with their doctor. So the question is not whether physicians and patients will use the technology, it is the “value proposition” for specific uses of PHRs that needs to be clarified.

The Varying Uses of PHRs

The NCVHS has drawn distinctions among different PHRs according to certain attributes, such as their contents, the source(s) of information they draw from, who controls the data, and so on. These are important differences, but it is also helpful to consider the different proposed *uses* of the PHR. PHRs can potentially be used for a variety of purposes, some of these applications might have more appeal to certain audiences than others.

Promoting Communication

PHRs can facilitate patient-physician communication, including for scheduling appointments, receiving testing or treatment instructions, asking questions and renewing prescriptions. Improving such communication may be of greatest value to people with chronic illness, or those caring for someone with a chronic illness, which might explain why these audiences are most likely to report high interest in PHRs.

Promoting Data Use

The data in PHRs can also be useful for tracking diseases across populations, for quality control and for marketing. These types of uses might be more appealing to purchasers, payors, public health officials, and industry; and some of these uses have a strong immediate business case. At the same time, however, such uses of PHR data might raise concerns among patients and physicians. Using the data in PHRs for marketing or public health surveillance might lead patients to worry about privacy, for example, while physicians might harbor concerns over having PHR data used for monitoring quality of care if the data in PHRs are not perceived as reliable or complete.

Promoting Patient Responsibility

A third major set of uses for PHRs is to increase patient responsibility, including by empowering patients to serve as “stewards” of their own health data and increasing patient engagement in managing their own health care. PHRs can deliver teaching materials, clinical prompts, and other management tools to patients. Moreover, as noted in a 2008 *Journal of the American Medical Informatics Association* article, “by placing the patients at the center of health care data exchange and empowering the patients to become the steward of their own data, protecting patient confidentiality becomes the personal responsibility of every participating patient.”

These three broad types of activities – promoting communication, data use, and patient responsibility – are related, but distinct sets of functions. Therefore, in addition to considering the challenges and opportunities in adopting PHRs for each of these uses, it is appropriate to question whether a tool created for one purpose will be effective when used for different purposes. For example, where billing systems have been used in efforts to monitor and improve the quality of care, they have been notoriously unreliable for the latter purpose. This was demonstrated with PHRs recently, when patients found inaccurate diagnoses in their personal Google Health records as a result of the PHR being populated with claims data. As Dr. Paul Tang noted, such inaccuracies are potentially of clinical relevance – for instance, a patient with a false diagnosis of a prior bleeding disorder in their PHR (based on claims data in which a bleeding disorder was a “rule out” consideration prompting a lab test) might not be given life-saving thrombolytic therapy during an acute myocardial infarction. One response to these concerns has been that patients and physicians should sit down and review the data in the PHR together. This would be ideal, though the majority of physicians in our survey expressed concerns regarding non-payment for time spent reviewing PHRs and also that sharing PHR data might impose additional liability risks for them. In sum, these concerns suggest that tools to facilitate data quality management must be part of any effective and useful PHR.

Also, if a PHR is promoted to one set of users for one purpose (such as to facilitate communication) but to another set of users for other purposes (such as for reimbursement), there is the risk of creating poor quality information, gaming of the system, and mistrust among various PHR users. Any time a new tool is said to both improve quality and reduce costs, there is the possibility that some users will believe the ‘real’ motivation is cost-savings rather than quality improvement, which can hinder trust, cooperation, and adoption.

Interoperability and Affordability of PHRs and EHRs

A series of issues have been frequently listed as the key challenges to the use of PHRs by physicians. These include costs, and standards and interoperability.

For both patients and physicians, issues of cost and interoperability are closely related. Because most people will be unwilling to devote a lot of time or additional resources to creating and filling with data a PHR de novo, most experts believe that PHRs will need to be self-populating with key data, such as lab results, medication history, basic demographics and core clinical information such as immunizations, allergies, and known medical history. Such self-populating PHRs will presumably become more common as the relationships between PHR companies and EHR vendors, lab facilities, pharmacies, and other services are more integrated. At the moment though, the least-cost PHRs are “tethered” products that are run by clinics, hospitals, health plans or employers. In these cases, the PHR is, more or less, a patient-facing version of an existing EHR. Patients may be able to add information to this record, or to interact with it in various ways, but they do not need to spend any time inputting data to gain some value from it. Of course, they are also tethered to the system that created the PHR, and it might be difficult to add information from other data sources or to transfer the PHR data elsewhere.

From the physician’s standpoint, a similar analysis applies. While a PHR product might be “free” for the physician, the time required to examine it, add information to it, and use it in medical decision making is not. Additional costs would be associated with PHR data that might be “incomplete, inaccurate, or difficult to verify, resulting in liability concerns for physicians.” As one physician put it, “The last thing I want is for my office staff to have to deal with patients arriving at the front desk with multiple, proprietary PHRs in a host of different formats and containing all sorts of unverifiable information.”

As noted above, in our survey, the majority of physicians expressed concern over the amount of non-reimbursable time it would take to review PHRs with patients to ensure their accuracy. For this reason, an EHR with a patient portal comprising the PHR – i.e., a tethered product – will be appealing to physicians. But even so, the cost concerns with PHRs will parallel concerns over the cost of EHRs more generally. For some large practices, EHRs have been associated with cost savings and revenue increases, but for many small practices the cost of purchasing and maintaining an EHR has been prohibitive and unmatched by any significant offsetting increase in revenues. According to several studies, the typical acquisition cost for an electronic record system runs upwards of $40,000, with annual operating costs of $2-16,000 per physician for smaller practices. Most U.S. physicians practicing in small groups state that these cost concerns have been a significant barrier to EHR, and hence PHR, adoption.

In order to address the cost concerns associated with EHR adoption and use rates, ARRA provides substantial financial incentives ($19 billion over a specified five-year period) to help physicians and hospitals purchase and implement EHRs. Beginning in 2011, Medicare physicians who implement and report meaningful use of qualifying electronic EHR will be eligible for incentive payments up to $44,000 over a 5 year reporting period. While ARRA includes a provision that will reduce Medicare payments (starting at 1 percent) for physicians who do not use EHR systems, this does not take effect until 2015, and there are exceptions for significant hardship cases. ARRA also provides incentives under the Medicaid program for EHR adoption and use by physicians, hospitals, and other health care providers. A key element to the widespread adoption and meaningful use of EHRs is the development of uniform electronic standards that allow various systems to communicate with each other. ARRA requires the Department of Health and Human Services (HHS) to develop standards, including interoperability, by December 31, 2009. In order to achieve a coherent EHR environment, systems will need to be highly connected, secure, affordable, and be integrated into the typical workflow of medical practices as diverse as those in large hospitals, community health centers, and among rural solo practitioners.

Concerns Over the Privacy and Security of PHRs

The most commonly recognized barrier to using PHRs is the risk of confidentiality or security breaches. Preserving the confidentiality of patient information is an ancient ethical precept in medicine – a cornerstone for patient trust in physicians – that physicians take very seriously. In an era when a patient's sensitive health care information can be made public with the click of a mouse, it is imperative that strong privacy and security standards and protections be in place and be enforced against all parties that exchange, use, disclose, store, or otherwise handle patient health information.

To address privacy and security concerns over the use of PHRs, ARRA requires the Federal Trade Commission (FTC) to promulgate by August 16, 2009, interim final regulations on breach of security notification requirements for entities not subject to the Health Insurance Portability and Accountability Act (HIPAA) such as PHR vendors. ARRA also requires HHS and the FTC to study potential privacy, security, and breach notification requirements and submit a report to Congress by February 2010. Until Congress enacts legislation implementing any recommendations contained in the joint FTC/HHS report, the FTC is authorized to enforce breach notification requirements against PHR vendors and PHR related entities that fail to appropriately notify customers in the event of a security breach.

Notification following a breach, while important, remains a poor remedy for broken trust. In our physician survey, almost two-thirds of physicians were concerned that PHRs might not have adequate privacy protections and almost the same number agreed that "there should be better enforcement of patient privacy laws" to promote record sharing. The AMA supports federal efforts to apply the HIPAA Rules to directly cover additional parties involved in the electronic exchange, storage, use, or handling of health information that are not currently covered by the HIPAA Privacy and Security Rules. Patients must believe in the confidentiality and security of their records for any PHR system to work. As we continue to move toward the widespread electronic exchange of health information, including through PHRs, protecting the confidential health information that patients entrust to physicians must remain a central element.

In conclusion, physicians stand ready to use PHRs as a key linkage tool within the clinical relationship to improve communication, care and outcomes. Yet a number of physician concerns should help shape the evolution of PHRs and maximize their utility while minimizing any potential risks. A summary lesson from our survey findings is that the data in PHRs needs to be of good quality, secure, and in a format that is useful. Physicians understand that more data is not always better. It is critical that PHRs not be simply a data repository, unchecked, with mounds of information that the doctor and patient are expected to sort through and be accountable for. Such a PHR would not be helpful – and if the data are inaccurate, it could be extremely harmful. On the other hand, if PHRs evolve to include multiple applications with direct clinical utility, such as functionality to analyze data as it is added and highlight key findings (e.g., if doctors and patients can set warning parameters so that worrisome data are flagged for further attention), then PHRs will serve as important tools for improving quality health care.

The AMA thanks the Subcommittee for inviting our input and look forward to continuing to work with you to address these important concerns.