

Detailed Analysis of Breakthroughs

1. My Personal Health Record (PHR)

Background

A personal health record (PHR) can be a powerful tool, but variability in the current set of products makes it challenging to assess the utility to patients. Until there is a common definition of what is meant by a PHR, it is difficult to clearly assess the benefits and risks to patients. To clarify, some PHRs are stand-alone platforms that do not link to patient health records or claims data, requiring all inputs to come directly from patients or other authorized users. Other PHRs can be integrated into health care delivery and claims systems such that drug, lab, and other procedure claims automatically populate the patient's PHR. This type of system is more commonly provided by medical institutions or regional health information organizations that have worked to automate such functions. This latter scenario would seem to provide the greatest value to patients, but requires additional supports to make operational. One further consideration for PHRs is that, while some are affiliated with entities covered by the HIPAA privacy rule, others are not.

Benefits

- Readily understood by consumers as having great potential for avoiding medical errors (for persons with drug allergies, for example)
- Patients, their families, and providers could benefit from the convenience of accessing and sharing data easily
- Quality monitoring entities could reduce the cost of provider compliance and data collecting if data could be downloaded from a PHR/EHR rather than requiring paper chart extraction
- Convenient and valuable for patients with numerous health care encounters (e.g., seniors and those with chronic disease)
- Linked with an EHR, its deployment requires consideration of numerous policy and technology requirements. For example, it would test the capacity to build reliable firewalls to preserve privacy and security of information
- Linked with an EHR, it could facilitate more regular exchanges between patients and their health care providers
- Despite the numerous cons associated with tackling PHRs as an initial breakthrough case, there may be some value in using it to highlight the critical importance of dealing with major policy issues, find out what consumers really want, and develop recommendations for synchronizing PHRs with EHRs.

Issues of Concern

- Highly variable product offerings – some may be better than others, but there is no way for consumers to evaluate that now
- Raises privacy and security issues that must be addressed, as many PHR entities are not covered under HIPAA

- Potential privacy challenges include fear of access and misuse by current or potential employers and insurers as well as desire to keep information about possible health issues from family members
- The distinction between a PHR and EHR should not imply that patients have any less access to or control over their EHR than they do over their PHR
- Systems not in sync with a complete EHR lack full value; as a stand-alone tool, it is only a record keeping system for patients
- The tool is only as valuable as the level/frequency of consumer input
- Not available or viable for some populations

Comments

- The distinction between the PHR and the EHR is unclear
- Scope of the record is not clear, which is of particular importance for seniors or those with serious disabilities. Should both PHRs and EHRs have capability to incorporate, for example, living wills, medical power of attorney, and organ donor transplant authorizations?
- Completeness and accuracy of information is of high importance. Must be able to be updated regularly and also capable of retaining data for long period of time (EKG results of 20 years ago, for example)
- Cost of access is of reasonably high importance. Ideally there would be little or no cost to the patient, but if there is any, it should be affordable for lower income families and seniors.

2. My Medication Record

Benefits

- Depending on the system design, it is feasible to achieve in the near term. It allows for significant patient engagement in health care (i.e., record keeping and information sharing). Linked to an information resource, it could provide patients with opportunities to learn more about their medications, potential interactions, etc. It represents an important step in centralizing medication information, offering significant clinical benefit. It represents a critical element of any EHR or PHR, so will identify policy issues that should be addressed broadly.
- If data quality is high, and information made available to providers on a regular basis, it would help avoid medication errors, duplications, etc.
- It could and should provide users the ability to record adverse events associated with their medications, and submit the information electronically to the prescribing clinician

Issues of Concern

- A lot can be ascertained from the medication people take. Security and privacy issues must be addressed up front
- The medication record may not reflect the reality of what a patient actually takes. It's possible that clinicians would record all that is prescribed, whereas patients might record only what they take

- Unless it is patient-populated, the record likely would not include critical information about over-the-counter medications, vitamins, and supplements
- Unless the record is updated frequently and shared with multiple providers, it will not address part of the root problem
- It is not necessarily technology dependent if the patient is the source of information/input

Comments

- The breakthrough description does not specify whether this is a patient-input system, a provider-input system, or the roles of payers or PBMs. The utility of the tool will depend on the model.
- Either way, it is critically important that patients have access to the record, and have the ability to add to/modify the record.
- The medication record provides opportunity to build an audit system of who has accessed information. Patients should have access to this information
- Study after study, over decades, shows that consumers walk out of their doctor's office and their pharmacies with prescriptions...without knowing exactly what the drug will do, what its side effects could be, or other drugs or nutritional supplements with which it might interact adversely. Any e-prescribing system must strive to improve this situation and overcome health literacy issues as a vital core function.

3. My Health Record Locator

Benefits

- A locator system enables access to knowledge of any type of care by any type of provider at any point in time.
- It has critical information sharing potential, particularly as a backup resource – for at least identifying episodes of care
- It would/should provide patients with a resource for knowing who has accessed their medical records
- Because it points to care transactions without identifying actual health information, it raises fewer privacy concerns/risks than a fully detailed electronic record

Issues of Concern

- Clinical information must be separate and secure from the locator to preserve privacy.
- Development of the locator requires identification of and agreement on the core data elements that would be available through the system.
- It is unclear whether patients have ability to keep information out of the locator system or completely opt out of the system.

Comments

- Would rely on a secure network and stringent requirements for systems access and authentication
- This type of system could be particularly important for patients not enrolled in EHRs, as it could be the only means of determining a complete medical profile

4. My Registration Information

Benefits

- Likely feasible in the near term
- Imparts immediate value and recognizable benefit to patients (no one likes to fill out duplicative forms, and it seems to be a common “pain point”)
- Provides clinicians with core set of important patient data

Issues of Concern

- Data could be subject to change on a regular basis – how would the system update and populate “linked” systems?
- It is not clear that patients would be able to control who gets the data.
- It only provides benefit to those patients and clinicians in the system, so if only 3 of a patient’s doctors are linked, but 4 are not, the patient still has to fill out a lot of forms.
- It may not force discussion of key policy issues that are central to the ultimate goal of EHRs and PHRs, depending on how much and what types of information is included in the registration

Comments

- It could prove challenging to identify the “core” set of data elements
- It is unclear whether this could really exist independent of a broader EHR or otherwise interoperable system

5. Electronic Medical Records

A fully developed EHR, supported by interoperable systems that link all patient health records regardless of physical location, would facilitate transmission of important patient data to relevant and authorized clinicians, allow for communication of such information between authorized clinicians and other relevant parties, and enable improved patient/clinician communications. Given the current level of health IT investment and integration, it is unrealistic to move immediately to this end goal. Rather, many of the breakthrough scenarios should be perceived as initial steps in building the framework and establishing the policy and technical specifications for such a system. It is for this reason that we encourage the AHIC to focus on breakthroughs that not only will achieve near term benefits for consumers, but also serve as a basis for achieving fully integrated EHR systems in the not-too-distant future.

6. E-prescribing

Benefits

- This breakthrough would achieve clear value for patients. There is potential to reduce medical errors through e-prescribing. With polypharmacy on the rise, experts widely acknowledge gaps in quality of care in this area. E-systems have a clear corrective mission.
- It is clearly achievable in the short term.
- The system would enable information sharing between providers, but would not necessarily engage patient unless system is linked to a medication record.
- It most likely would improve confidence as people perceive more coordination among health plans/PBMs, doctors and pharmacies in drug prescribing and medication management.

Issues of Concern

- Without linkage to a medication record, including immunization records and adverse drug event (ADE) reporting, electronic prescribing does little to empower the patient and give them more control and understanding of their health care
- On its own, e-prescribing will not force consideration of more serious policy questions related to longer-term goals of EHR/PHR, including privacy and security issues

Comments

- The disconnect between e-prescribing and ongoing care and care coordination produces less than optimal patient outcomes and quality of care. Leveraging electronic tracking, monitoring and reporting capabilities to achieve a feedback mechanism, HIT has the potential to dramatically improve the health system and quality of care. This breakthrough can and should integrate adverse reaction reporting into the e-prescribing design.

7. Quality Monitoring & Reporting

Quality monitoring and public reporting should be a by-product imbedded in many of the proposed breakthroughs. For example, electronic health records, e-prescribing, chronic disease monitoring, child immunization records, employee empowerment tools, all represent opportunities to systematically gather and report comparative information to consumers. The EHR breakthrough, in particular, should require that standardized performance measures and their corresponding data elements be imbedded in these products in order to enable providers to assess and report on their adherence to evidence-based medicine and clinical guidelines.

8. Chronic Disease Monitoring

HIT potentially advances opportunities for quality improvement for both patients and clinicians through convenient and timely access to the information needed to monitor an individual's condition. Patients with chronic health conditions can be advantaged through electronic decision supports designed to help them better manage their own care. Many experts assert that more engaged patients are likely to have better health outcomes; decision support tools potentially can stimulate patient engagement. Clinicians also benefit from having access to electronic decision supports that facilitate development of practice-based patient registries, access to evidence-based guidelines for specified chronic conditions, reminders, laboratory and other tests results and other support to ensure that appropriate care is offered in a timely manner.

9. Child Immunization Record

Benefits

- Not a volatile issue from privacy perspective
- Perceived by consumers and clinicians as a real convenience (minimizes the “hassle factor”). Frequent need for data (school, camp, travel, sensitivity reactions).
- A commonly used indicator of quality of performance of primary care provider
- Would be welcomed by public health officials to assist in assuring complete immunizations
- Should be feasible within 2-3 years, as much of this data is collected and transmitted electronically now
- Good test case for elements of other potential breakthrough selections, including My Personal Health Record, My Health Record Locator, Electronic Health Record, Quality Monitoring and Reporting, and Biosurveillance

Comments

- Potential users include parent or guardian, state or local child immunization registry, physician or other primary care provider, quality monitoring entity (aggregate data only, no patient ID needed)
- Completeness and accuracy are of high importance. It is important to avoid duplicate immunizations.
- Accessibility for patient/parent is of high importance. Must be possible to access personally or have system in place for authorization of access so it can readily be retrieved. Could involve access from sites out of country (children of migrant laborers, recent immigrants, travelers).

10. Employee Empowerment Tools

Benefits

- As consumers face ever higher health care costs, we have an interest in controlling them. Education about wellness and prevention may be valuable. A key question is whether and how providing that education ties into employment.
- To the extent workers have health insurance through their employer, there may be benefits that are more easily applied to the full population of those enrolled in the employer's health plan (i.e., disease management).
- There is potential for consumers to be partners in their own health care if they have access to and control of their own health information.

Issues of Concern

- This breakthrough raises very serious privacy concerns: firewalls must exist between personal medical information and employers and/or insurers. Without the assurance of privacy, workers will have very real concerns that their health status will affect their employment and/or insurance status.
- There is concern that these tools may be used to promote cost control over quality: using HIT to link employees to their claims data suggests a priority for cost savings rather than quality and may discourage employees from seeking health care.
- HIT implementation should not be used to market or promote specific health insurance products. In particular, health savings accounts, which require consumers to have high-deductible health plans, are no more appropriately paired with HIT and EMR/PHR than with any other insurance product if the goal is truly to improve quality and not just to control costs. In fact, if consumers believe HIT and EMR/PHR are being used to justify high deductible health plans and greater out of pocket costs for consumers, it will seriously undermine public confidence in and support for HIT.
- Links to relevant tools that would allow employees to educate themselves about specific diseases raise the possibility that employers might monitor queries by employees as signals of potential health risks that would affect their employment status.

Comments

- Most of the benefits of HIT for workers will be no different than for all other consumers, yet specifically linking HIT to places of employment raises many serious concerns. Until the emphasis on cost control and the privacy concerns are thoroughly addressed, this breakthrough should not be pursued.

11. Emergency Information Network

Benefits

- In an emergency situation, access to information about current health conditions, allergies, and prescription medications is vital.
- As evidenced by the database that was established for Hurricane Katrina evacuees, the development of a system that offers centralized, web-based access to critical information (such as prescription drug records) can happen quickly.
- Development of the system and value for patients can be clearly conveyed to consumers.

Issues of Concern

- Privacy and security protections can be diminished during disaster relief. In the event of an emergency, legal protections for consumers—including privacy protections for health information—are often waived. Furthermore, information is often disclosed to individuals and organizations (such as the Red Cross) that have no legal obligation to protect it.
- Ability of individuals to authorize information sharing diminished. In the event of an emergency, individuals' ability to authorize who sees their information could be diminished.
- Decisions about how to build and utilize these systems—especially if done quickly—often exclude consumer and patient advocates.
- Ability to access and amend data must be addressed: Patients *should* be able to access and amend their personal health information. Amendment requests should be honored in a more timely manner because of the implications of incorrect information in an emergency situation.

Comments

- To better protect patients, an emergency information network breakthrough should establish an open process regarding development of the system allowing both consumers and patient representatives to weigh in.
- Patients must be given notice about the development of such as system and be given the opportunity to opt-out prior to its development. If this is not feasible, they should be informed about where their medical information is stored and be given the opportunity to opt out as soon as possible.
- Even in emergency situations, all information collected should be afforded the full protections of the Privacy and Security Rules as soon as doing so does not present a serious concern to public health.
- In emergency situations, access to the database should remain tightly controlled, and there should be protocols in place to ensure that only authorized individuals have access to the information.
- The Department of Health and Human Services should make every effort to target future waivers of laws protecting patients and their information as narrowly as possible.

12. Biosurveillance & Pandemic Surveillance

Benefits

- Surveillance and epidemiological studies are an important part of achieving optimal public health and adequately responding to disease outbreaks, whether natural or intentional.
- Even prior to 9/11, real-time public health surveillance systems were being conceived and developed. Since then (and with federal support), “syndromic surveillance” systems have continued to grow throughout the country.
- Biosurveillance systems can allow for aggregate data sharing. Systems such as the NYC syndromic surveillance system report aggregated data on a daily basis to the NYC Department of Health and Mental Hygiene, an important element of establishing a system that respects patient privacy.

Issues of Concern

- So far, there hasn’t been a high degree of public visibility or a transparent process with outside oversight. Diverse systems are cropping up, and it is extremely difficult to determine where systems exist, what types of entities are involved, and how they are operating. Some operate exclusively among public health authorities while others involve the private sector. There has been an absence of public discourse about how much information is needed for these systems, who should see the information, and for what purposes.
- Privacy and security of data does not appear to be a priority. There is no clear, national law for these activities. Information is being collected, used, and stored without any regulatory guidance or enforcement.
- Has been a lack of planning about how to protect information and patients in the event of an outbreak and the corresponding investigation. There hasn’t been a strong effort to create agreement among public health authorities and law enforcement about how to handle protected health information in the event of an investigation, how to conduct investigations, and where responsibilities are divided.
- The collection and use of data has not been limited to biosurveillance. To the contrary, by and large, these systems have been used—and will continue to be used—for epidemiological studies. Without an upfront, open debate to address concerns about privacy and public trust, the information is being accessed for dual uses.
- Patients do not play an active role in the development and operation of these systems. Patients do not authorize information sharing, do not have access to information shared through these systems, and currently do not have adequate notice about their function.

Comments

To better protect patients, biosurveillance and pandemic surveillance breakthroughs should:

- Encourage the development of a clearinghouse that collects information about systems that are being developed across the country. The clearinghouse should

catalogue who is developing what systems, how information is being collected and used, and information about any laws at play.

- Establish more transparency, so that patients are better notified and informed about the existence of the systems.
- Encourage the development of voluntary privacy and security standards where strong laws are not at play. The standards should direct that there is no collection, use, or sharing of individually-identifiable information.
- There should be some binding legal agreement between law enforcement and public health authorities that clearly outlines respective roles.
- There have to be sanctions for any violated standards, and there needs to be adequate training and coordination to ensure adoption and implementation.

13. Adverse Drug Event Reporting & Notification

Adverse Drug Event Reporting & Notification should be a component of the health care delivery system as enabled by information technology. This breakthrough is not sufficiently distinct from others to stand on its own. It should be considered as an integral part of other breakthroughs such as My Medication Record, E-Prescribing, and Child Immunization Record.