HIE Patient Consent Model Options

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Health information exchanges (HIEs) continue to expand across the nation as organizations prepare to meet the stage 1 meaningful use criteria. A 2010 eHealth Initiative survey found that there are currently 73 operational HIE initiatives, up from 57 in 2009.

During this rapid advancement, HIEs continue to struggle with how patients will become part of an HIE while protecting the privacy and security of the individual. Those involved with establishing HIEs should understand the various patient consent models available and the state and federal regulations that restrict some data from being exchanged.

Patient Consent Models

According to a white paper prepared for the Office of the National Coordinator for Health IT titled "Consumer Consent Options for Electronic Health Information Exchange: Policy Considerations and Analysis," there are five core consent options for electronic exchange:[1]

No consent model. In this model, patients' protected health information (PHI) is automatically included in an HIE-patients cannot opt out. This model may be found in states that do not have requirements beyond the HIPAA regulations. However, HIEs may choose to notify patients that their PHI will be used in the exchange and educate them on how their information will be used.

Opt-out model. In this model, patient PHI is included automatically in the HIE unless the patient opts out completely. A patient's information would either be exchanged only where mandated such as for health surveillance activities or never included in the exchange. Most HIEs prefer the opt-out model.

This model is an all or nothing choice. Patients cannot restrict portions of their information in this model.

Opt-out with exceptions. This model provides more options than the basic opt-out model described above. In this model, patient PHI is automatically included in the HIE unless the patient opts out. It also allows patients to include only select data in the HIE. Patients can exclude specific data, limit the exchange to specific providers or organizations, and limit the exchange for specific purposes.

At this time, few HIEs have implemented this model. There are technical and operational challenges around limiting the data for exchange purposes at this time. HIEs must be technologically advanced to implement this model.

Opt-in model. In this model patients must consent to have their PHI included in the HIE. No PHI is included without patient consent.

Once a patient has opted in, there are no choices limiting what information is sent or to whom. Similar to the opt-out model, it is all or nothing.

Opt-in with restrictions. As with the opt-in model, patients must consent to have their PHI included in the HIE. Patients may also allow a subset of select data to be included. Patients must define what information is to be sent, who it is sent to, and for what purposes the information may be used.

Like the opt-out with exceptions model, there are technical and operational challenges with limiting the information allowed and exchanged in this model. At this time, most HIEs are not able to define their systems with this type of granularity.

Patient Preference versus State and Federal Laws

With reports of privacy and security breaches increasing, patients will most likely want to have control over the type of PHI that may be shared. There may be times when patients want to restrict specific information from certain providers or even restrict it from the HIE in its entirety.

Patients may want to determine the time frame for when their PHI is available in the HIE and expect their information to be taken out after that point in time. They may also want to define the purpose for which their information is shared.

As noted above, some HIE models allow this type of granularity. However, there may be times where state laws supersede the patient's restrictions for purposes such as health surveillance activities. State and federal laws will also drive the need to separate data based on the nature of the information. For example, the federal Confidentiality of Alcohol and Drug Abuse Patient Records (Part 2) regulation prohibits redisclosure of substance abuse records.

State and federal laws will define sensitive data, though patients may want more information restricted than what the laws require. HIEs must identify what individual pieces of data are eligible for the exchange and ensure only those pieces flow into the HIE.

The HIE's consent model and software functionality will determine its ability to specify exactly what information may be sent, to whom, under what circumstances, and for what period of time, or the granularity allowed.

HIEs must also identify unstructured data, especially information from legacy data. This information will not be able to be managed through the application of consent management systems.

HIE Progress at the State and Federal Level

The federal government continues to achieve new milestones in helping HIEs take root across the US. In February, the Office of the National Coordinator for Health IT launched Direct Project pilots in Minnesota and Rhode Island. These states will soon be joined by New York, Connecticut, Tennessee, Oklahoma, Texas, and California.

The Direct Project is a streamlined version of the Nationwide Health Information Network that sends data through secure messaging over the Internet. The project will enable healthcare providers to replace mail and fax for simple and secure transmittal of PHI. This is a significant step toward meeting ONC's commitment to make HIE accessible and practical for the nation's clinicians.[1]

Note

1. Blumenthal, David, and Aneesh Chopra. "EHR Data Exchange Highlight of Direct Pilot Program Launch." February 2, 2011. http://healthit.hhs.gov/blog/onc/index.php/2011/02/02/direct-project-pilot-programs-launched.

Educating Patients

Patients who do not understand or trust HIEs may choose to opt out but still have their information shared in the traditional manner of faxing or mailing. Whether patients opt in to the HIE or stay with the traditional means of exchanging information, they need to be educated on the benefits of HIEs and how PHI is transmitted.

Privacy and security will continue to be a patient concern and must be addressed in the patient education. In addition, it will be up to organizations and providers to ensure patients understand the benefits and risks of not sharing their information. For example, patients who opt in to the HIE ensure their physician has the most up-to-date information, including current medications and health concerns, available in emergency situations.

Ideally, HIEs will be able to offer patients the granularity they desire. However, engaging patients and determining their preferences for sharing their PHI can be both technically and operationally challenging.

Providers are considered key players in identifying and honoring patient preferences. But some providers may see educating patients and identifying patient preferences at the point of care as a stumbling block. They may be overwhelmed with the process of identifying the patient preference, recording that information, and administering the preferences upon release.

To help facilitate the process of educating patients, AHIMA has developed a brochure with fundamental information about HIEs and how PHI will be used. The brochure outlines what an HIE is and the benefits of participating in one. It is available for download at www.ahima.org/resources/hie.aspx.

Note

1. Goldstein, Melissa M., and Alison L. Rein. "Consumer Consent Options for Electronic Health Information Exchange: Policy Considerations and Analysis." March 23, 2010. http://healthit.hhs.gov/portal/server.pt/community/healthit_hhs_gov__privacy_and_security/1147.

Reference

AHIMA. "Health Information Exchange (HIE)-What Does It Mean to Me and My Doctor?" www.ahima.org/resources/hie.aspx.

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