Health Data's Second Life

Save to myBoK

by Chris Dimick

The use of health data for secondary purposes has been increasing, and federal agencies and industry organizations are exploring the need for more guidance.

Data in a health record don't rest when care is complete and a bill is drawn up. Once treatment and reimbursement are finished, data are often sent off for a variety of secondary uses. The use of health data for purposes such as quality measurement and population health tracking is an ever-growing practice. Though the secondary use of health data is expanding, experts say regulations and standards generally are still lacking. That may change as an array of industry groups are at work studying the issues and preparing recommendations on the appropriate use of health data once care and reimbursement are complete.

Use, Scrutiny on the Rise

Secondary use is any use of health data for reasons other than direct clinical care. These can include public health monitoring, tracking consistency and quality of care for clinical use, and reporting quality of care measures to government and private agencies.

As stewards of the health record, HIM professionals can be responsible for issuing data to secondary users. Therefore they have a fundamental interest in the topic. "This is an extension of issues that HIM professionals should be concerned about," says Meryl Bloomrosen, MBA, RHIA, associate vice president of American Medical Informatics Association (AMIA). "[It represents] another point on the continuum of managing health information."

Many patients don't understand that their health information could be used secondarily after discharge, says Jon White, MD, health IT director with the Agency for Healthcare Research and Quality (AHRQ). But people should be concerned about what happens to their medical information.

"A very clear concern is the issue of privacy as well as consent for the information that is being used," White says. "Once your HIV status gets out there, it doesn't come back. You can't recapture that. So people have very legitimate concerns about who gets access to their health data and that it is not going to be used against them."

Standards for secondary use of health data are not clearcut. Because of this gap, several healthcare-focused agencies and organizations such as AHRQ and AMIA have undertaken work with the hope of creating a national understanding and framework for secondary data uses.

Though these organizations and their work vary, their goals are primarily the same: formulate appropriate and effective secondary use of health information to improve healthcare. Following are some of the organizations at work and the work that can be expected from them.

Seeking "Full Public Comment"

In June of this year AHRQ issued a request for information on the concept of health data stewardship and secondary use, White says. AHRQ posted all comments publicly to its Web site, www.ahrq.org, and plans to create a "qualitative summary" of the public testimony, which it will also share online.

The work is "meant to be a public service to better inform the discussion of these various stakeholders," White says. "We felt like there hadn't been the opportunity for full public comment on the subject."

As part of its goal to improve general understanding and further discussion, AHRQ also will provide the results to AQA, an alliance of physicians, payers, consumers, and public and private entities that focuses on physician-level performance measurement. Formed in 2004 by the American Academy of Family Physicians, the American College of Physicians, America's Health Insurance Plans, and AHRQ, the alliance will use the information in future secondary use projects and discussions.

Benefits of Clarification and Guidance

In October eHealth Initiative (eHI) released "Blueprint for Improving America's Health and Healthcare through Information and Information Technology." The document addresses strategies and actions for using health information to drive different components of healthcare improvement. One of these is improving population health.

Population health studies are major secondary consumers of health data. The eHI blueprint committee developed strategies and actions for using health IT to facilitate monitoring and research and improve population health, says Janet Marchibroda, eHI's CEO.

The organization's work on health information exchange also involves secondary data use. Earlier in the year, eHI released research regarding sustainable business models for exchange networks. That research notes that while the focus should be care delivery, an HIE network should plan for the use and exchange of data for secondary initiatives such as population health, Marchibroda says. The research also reports that incorportating secondary data use promotes full use of the HIE system and interests a larger share of a community's healthcare stakeholders, important to ensuring the network's sustainability.

The organization will conduct learning labs in the field that focus on secondary data uses. "We are going on the ground, and we are testing and evaluating the feasibility of using clinical data sets for secondary uses," Marchibroda says. The information gathered from this initiative will be made available to the public.

Though standards need to be implemented, the eHI blueprint states that secondary data use laws do not need to be changed, only clarified. "All the stakeholders in healthcare at the national and local levels would benefit from some common principles around things like purpose specification, permitted uses, disclosure, consent," Marchibroda says.

Policies to Build Public Trust

AMIA held in-depth conferences to discuss secondary use of health data in 2006 and again in summer 2007. The organization believes that a public policy framework regarding secondary use of health data needs to be formed, and it wants to help develop that policy, says AMIA's Bloomrosen. "We feel that technology has outpaced policy," she says.

An urgent need exists to formulate a public policy framework regarding secondary use of health data to "ensure public trust as the national health information network evolves," AMIA states on its Web site. Though secondary use of health data can enhance healthcare experiences and expand knowledge about disease and treatment, secondary use also "poses complex ethical, political, technical, and social challenges."

Standards for the Content, Too

Public and private organizations that request performance measurement data have different sets of requirements and specifications for reporting results. Healthcare organizations must assess each component of a measure's requirements to ensure complete and accurate reporting.

As some industry groups work on the appropriate uses for secondary data, others are discussing standards for the actual data, evaluating how electronic clinical information can be repurposed for various secondary purposes such as quality measures and public health reporting.

HL7 Clinical Interoperability Council

Health Level Seven's Clinical Interoperability Council met for the first time this fall, with a goal of coordinating the development and harmonization of clinical data content. More than 50 organizations and professional clinical societies have active data content projects in the works, and the council hopes to help prevent overlapping and inconsistent results.

Its initial focus is the creation of a master set of data elements and corresponding attributes, including information from existing data sets and initiatives, to support the creation and loading of data elements into a shared repository. For more on the council, see "Making Sense of Standards" by Ed Hammond and Brian McCourt in the September 2007 *Journal*.

Health Information Technology Expert Panel

Another group focused on facilitating secondary data use through content standards is the Health Information Technology Expert Panel. It convened in response to a recommendation by the American Health Information Community (AHIC) quality work group to accelerate efforts to identify a set of common data elements to enable automation of a core set of quality measures from AQA (for ambulatory care) and the Hospital Quality Alliance (for hospital-based care).

Through National Quality Forum leadership, the panel's primary goal is to prioritize the types of data elements required to support quality measurement in electronic health records. As part of this process, the panel is assessing the quality of each data element and feasibility for collecting the information in electronic formats.

Information from this group has been incorporated into specifications from the Healthcare Information Technology Standards Panel that support the AHIC use case on quality. The panel is also evaluating methods to incorporate functional criteria into future certification requirements from the Certification Commission for Healthcare Information Technology.

Discussions at AMIA's 2006 Invitational Conference on Secondary Use of Health Data are boiled down in a white paper that summarizes the major issues. These include the need to:

- Address patient privacy issues to ensure public trust
- Develop use policies and processes that catch up to new technological capabilities to merge, link, re-use, and exchange data
- Attract additional attention and leadership on the topic at state and national levels

The work generated from the 2007 conference will be used throughout the year to develop work products, and it may spur future AMIA initiatives, Bloomrosen says. At the 2007 meeting, work groups discussed and developed a comprehensive taxonomy of use and users of secondary health data, reviewed the technologies that are used to de-identify and re-identify data sets, and defined data stewardship and related policy issues. The National Committee on Vital and Health Statistics (NCVHS) asked AMIA to finalize the draft taxonomy, which NCVHS will incorporate as part of its own initiative on the topic.

AMIA submitted version 1.0 of the taxonomy in September, as well as a checklist consumers can use to evaluate Web sites that collect personal health information. Both documents are available at www.amia.org.

Standards for Ensuring Quality, Easing the Burden

Both AMIA and eHI described their work in testimony to NCVHS during meetings in summer 2007. Titled "Ad Hoc Workgroup for Secondary Uses of Health Data," the July and August meetings were just two of five meetings NCVHS held this year to discuss the issue, drawing experts from around the healthcare industry. The committee will use the testimony to make recommendations on secondary use of health data to the secretary of Health and Human Services.

Barbara Siegel, MS, RHIT, FAHIMA, testified at the August meeting on behalf of AHIMA. Siegel, director of health information at Hackensack University Medical Center in Hackensack, NJ, at the time, related her firsthand experience in dealing with secondary health data requests, and she discussed AHIMA's position on the issue.

Hackensack's HIM department currently has six full-time employees collecting and distributing de-identified health information for a variety of public reporting quality programs, such as those sponsored by the Centers for Medicare and Medicaid Services and the Joint Commission.

Siegel testified to NCVHS on the secondary data issues directly relating to HIM. She discussed the challenges of determining which disclosures are appropriate when a patient has multiple health plans, as well as those challenges related to fulfilling disclosures in a part-paper, part-electronic record, a hybrid environment that is increasingly common in the industry. She also discussed the ambiguities around secondary data use that arise when provider organizations attempt to square HIPAA requirements with other federal and state requirements.

Siegel's testimony also addressed the increasing burden of fulfilling secondary data requests, an issue that AHIMA explored through a 2006 conference in collaboration with AHRQ and the Medical Group Management Association (see the related story on page 56).

Hackensack's HIM department fields a steadily increasing number of data requests from external organizations, Siegel reported to NCVHS. These requests come from third-party payers, health plans, state agencies, researchers, and others. Requests will only increase with the rise of electronic health records, she testified.

"It is the diversity of these requests, the lack of standards in process and data, and the fact that our industry has yet to achieve an interoperable electronic health record that present many of the issues you are addressing," Siegel told the NCVHS work group. "If we are to have quality data and data integrity, the healthcare industry must address these ambiguities and improve the standards for secondary data reporting and collection across all spectrums of care."

Why Now, What Next?

Several developments are pushing secondary uses of health data to the forefront. The recent focus on improving the quality of care through quality reporting initiatives, as well as related programs such as pay-for-performance, have increased the use of health data for nonprimary reasons, Siegel says.

AHRQ's White adds that the "extraordinary" rise in the cost of healthcare is causing the general public and lawmakers to put pressure on healthcare organizations to make care more effective, efficient, accurate, and affordable. Population health studies, which use vast amounts of secondary health data, are one avenue being explored to help address the problem of high healthcare costs, he says.

The increasing digitization of healthcare information also is making it much easier to use health data for reasons other than primary care. The development of electronic health record systems and the work toward interoperable health information exchange networks have increased the need to develop a policy framework regarding secondary health data use, says AMIA's Bloomrosen.

There are many organizations with an interest in secondary data use. NCVHS's meetings featured testimony from dozens of organizations and individuals. The coming year will see reports and recommendations from AHRQ, eHI, AMIA, AHIMA, and others.

HIM professionals naturally have reason to pay close attention to this topic, Siegel says, because it reaches the core of HIM practice. The secondary use of health data relies primarily on coded records. "Managing the record is our responsibility, and this information is coming out of the medical record," Siegel says. HIM professionals are at the origin of a record's accuracy, confidentiality, and security.

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