Empowered Patient: Preparing for a New Patient Interaction

Save to myBoK

by Chris Dimick

The movement to give patients better access to and control of their health information is giving HIM a new customer: the patient. That requires a shift in both operations and culture.

HIM, MEET THE new patient.

While a simple release of information on paper might have once been enough, this new patient is positioned to ask much more of the HIM department.

This patient will arrive at the HIM department with new awareness and legally backed requests-some requests, even, that HIM has yet to figure out how to fulfill.

Private, state, and federal initiatives have granted patients better access and new control over their health information. Laws like HIPAA and ARRA and private initiatives like AHIMA's Health Information Bill of Rights and the national push toward personal health records will change the way HIM professionals interact with patients.

While serving patient needs has always been a priority in the past, an HIM department's main responsibility has been maintaining a complete and accurate record of care and a legally sound business record for their facilities. This will continue to be the first priority. But as consumers, advocacy groups, and legislators push for patient access to facility records, the HIM department will find itself working with patients more frequently and in different ways, HIM experts say.

Some of these changes are already occurring; others will take effect over the next several years. But regardless of when the "new patient" shows up in the department doorway, HIM experts agree it is essential to be prepared-both operationally and mentally-to serve patient requests.

The Patient-centered Movement

Patient-centered healthcare describes efforts by patient advocates and sectors of the healthcare industry to put the patient, not the system, at the center of healthcare priorities and operations. The patient-centered movement strives to make the patient an active partner in healthcare, not just a healthcare recipient, says Deven McGraw, JD, LLM, MPH, the director of the Health Privacy Project at the Center for Democracy and Technology, based in Washington, DC.

Patient-centered healthcare "in some respects challenges the traditional medical model and gives patients a role in decision making," McGraw says. "Which means patients have to have information in their hands as well."

Patient-centered healthcare initiatives seek to make patients more financially responsible and accountable for their healthcare. In order to do this, patients need to "be in the data flow in some way, or be able to easily access their data and ideally communicate more efficiently and effectively with their healthcare providers," McGraw says, "which does require some system and workflow redesign."

HIM is integral to this patient-centered movement, as evident in recent federal laws like HIPAA and ARRA that specify rights patients have over their health information. HIPAA established basic patient rights to access information; ARRA extends many of those rights through modifications to the HIPAA rules.

Although patients have always been a customer of HIM, staff interaction with patients in the past did not extend much beyond release of information requests. But new patient-centered initiatives will soon change that, causing HIM to have more interaction with patients and devote more of their operations to fulfilling patient needs, says Wendy Mangin, MS, RHIA, the director of medical records at Good Samaritan Hospital, in Vincennes, IN. “We are going to be working in different ways with patients than we have before,” Mangin says.

Operations aside, HIM professionals will have to shift their mindset and culture as well to be more patient-centered.

“Patients have been coming to us for a long time, so I personally think we have always been patient-centric,” Mangin says. “But I think, and this is a very good thing, legislation has continued to drive that [patient-centeredness] and it certainly has affected what we do on a day-to-day basis. It needed to in some cases.

“There is the tendency at times to get protectionist about your information and maybe not be as willing to let it out.”

While the patient-centered movement has been advancing for decades, it did not really affect HIM until the early part of this decade when the HIPAA privacy and security rules took effect, according to Mangin.

The ARRA Impact on Operations

Provisions in the American Recovery and Reinvestment Act grant consumers new rights to access and restrict use of their health information. To varying extents, each challenges HIM departments to adapt their operations to meet the new requirements.

Accounting for Disclosures

HIPAA first required covered entities provide an accounting of disclosures of a patient’s record upon request. It excluded disclosures for treatment, payment, and healthcare operations. ARRA removes that exception for covered entities that use EHR systems.

Consumer groups fought for this patient-centered inclusion on the basis that patients should know who looks at their record, McGraw says. “This is a huge benefit to enhancing transparency for patients,” she says.

Meeting this requirement will require bridging a gap between the law and current technology. Most facilities do not currently have the processes or technical ability to track such access. Systems purchased prior to 2009 have until 2014 to meet the new requirements. Systems purchased in 2009 and beyond must meet the new requirements by January 1, 2011. However, as 2010 began, the industry was still waiting on the federal government to release technical standards for fulfilling the requests; a final rule is not expected until mid-year.

Once an EHR system is configured to track these disclosures, HIM staff will have to be trained on how to process and read the generated data in order to determine for patients if any inappropriate disclosures took place, Quinsey says. HIM will need to work closely with patients on these requests.

“This is going to be an enormous challenge,” she says.

Request for Restrictions

ARRA also gives patients new rights to restrict disclosure of their information. HIPAA stated patients could make a request for their health record to be restricted from access by certain people or entities. But facilities had the right to deny those requests, which they routinely did based on their attorneys’ advice, Roach says.

ARRA changed HIPAA to allow patients who pay for treatment in full out of their own pockets to request that the health records from that encounter not be released to their insurance companies. HIM departments across the nation are left to figure out how to ensure certain patient records are sequestered and restricted from disclosure, Quinsey says. New processes will have to be established to separate those restricted documents from the rest of the record. Even if a health plan requests patient records for an audit, the HIM department would have to restrict access to parts of the record if demanded by a patient, Roach says.

Though the logistics of restricting this information are unclear, Quinsey says answers must come soon in order to give patients the ability to exercise this right. Regulations necessary to enact the ARRA provisions are due this month from the Office for Civil Rights.

“I think that today with electronics we actually have a better shot at being able to guarantee these restrictions,” Quinsey says. “Having said that, we are on a major voyage of discovery trying to figure out what kind of controls we actually can exercise.”

Electronic Copies

ARRA also grants patients a right to receive an electronic copy of their medical record if a facility uses an EHR. This might seem a natural request from a patient’s point of view, but HIM professionals know most EHR systems currently do not have an easy way to produce an electronic copy of records.

HIM departments must work with their system vendors to develop a method to quickly produce electronic copies from their EHRs, Mangin says.

At Group Health Cooperative, Quinsey and her HIM staff are finding it difficult to produce an electronic copy of a patient’s record.

After talking with her EHR vendor, Quinsey found the only way to get a patient’s records onto a CD would be to print out the documents, scan them, then drop the scanned images on the CD. This laborious process is not practical for large-scale release of information production.

Given the situation, it will be necessary to explain to patients that, at least for now, producing their record takes much more than a “push of a button,” Goethals notes.

Aside from ARRA’s requirements, HIM departments should consider enhancing patient’s access to the electronic record merely because that is the form they will desire. Patients will increasingly want their information electronically. In order to provide patients with acceptable customer service, HIM needs to change their operations and thinking to meet those requests, Mangin says.

“Patients are going to expect this and are going to expect a lot faster service and access to that information than perhaps what they are getting today,” she says.

HIPAA Changed the HIM-Patient Relationship

In general, HIM professionals have always advocated that patients should have access to their information, says Carol Ann Quinsey, RHIA, CHPS, the associate director of HIM operations at Group Health Cooperative, based in Seattle, WA.

However, it was HIPAA that changed how HIM approached records management by requiring them to meet certain patient requests for information. Prior to HIPAA, state law varied regarding patient rights to access and receive a copy of their medical record. Some healthcare facilities even had restrictive policies on releasing records to patients, Quinsey says. But when HIPAA went into effect, it guaranteed patients the right to access, copy, and request amendments to their health records.

“There was certainly some patient empowerment that HIPAA provided,” says Michael C. Roach, MHSA, JD, partner with healthcare law firm Meade & Roach, LLP, based in Chicago. “I think a lot of people who didn’t have certain rights gained some rights.”

HIPAA permitted HIM to redisclose other facilities’ records to patients. This saved patients visits to other hospitals to retrieve their records. Another provision gave patients the right to request an amendment to their record. This was a big change for

HIM professionals, Mangin says, as staff first began to work with patients on the details of the record.

HIPAA also granted patients the right to access their medical record while still an inpatient. Several state laws had prohibited this act prior to HIPAA, only allowing the release of the record following discharge.

These provisions all challenged HIM operations to be more patient-centered, and they increased HIM's direct interaction with patients. Record requests increased after HIPAA, and more patients found their way to the HIM department, Mangin says.

ARRA Provisions Extend HIPAA Rights

The recent American Recovery and Reinvestment Act modifications to HIPAA will continue to change HIM operations and their interaction with patients.

Signed into law February 2009, ARRA was a major victory for patient-centered healthcare advocates hoping to give patients more control over their records in the new electronic environment, McGraw says.

Legislators included the changes to aid acceptance of the nationwide implementation of EHRs. In order for patients to accept this shift to EHRs, McGraw says, HIPAA needed to be updated to ensure highly portable electronic health records remained secure and private.

“HIM's interaction with patients was kicked up a notch with HIPAA, and I think ARRA is going to kick it up another notch,” Mangin says.

For covered entities using EHRs, ARRA extends the information the entity must provide under HIPAA's accounting of disclosure provisions and requires them to provide or transfer a consumer's health information in electronic format upon request. Further modifications give consumers greater ability to restrict access to or disclosure of their information. (See sidebar, [above], for more on ARRA's operational impact.)

The PHR Effect

Patient demand led Group Health Cooperative to create a personal health record (PHR) in the mid-1990s. The facility is located across from a Microsoft office campus, and tech-savvy patients routinely asked for a way to access lab results and communicate with their physicians electronically.

Group Health created myGroupHealth, giving patients a select view of their health information, Quinsey says. Today, patients can get records and schedule appointments through the system.

PHRs are a patient-centered initiative with both private and public support that is affecting more HIM professionals. There is no single format for them, but all involve the patient creating and maintaining, to some degree, a personal copy of their entire health history.

For now PHRs are only used by a small part of the patient population. But if more people begin using them, HIM departments performing release of information services will have to adjust to meet consumer needs.

Colleen Goethals, MS, RHIA, is an HIM consultant with Midwest Medical Record Association in Schaumburg, IL. Three years ago she began giving patient-geared educational sessions on use of the PHR in the Rockford, IL, area where she lives. Goethals called the HIM departments of the major healthcare providers in her area to tell them about her sessions and notify them that they may receive an increase in patients requesting their records.

Many of the departments were troubled by the news, not excited, she says. They worried that the presentations would send a flood of patients into their departments asking for medical records. Their staffs were not prepared to handle that kind of demand.

That did not happen, but as requests increase in time, Goethals expects more HIM departments will embrace this patient-centered initiative and add staff to support it. Though it will make more work for HIM, she encourages HIM professionals to promote PHRs with patients and adapt their operations to make it easier for people to get access to their information.

Regardless of whether PHRs become popular, HIM staff should take the time with patients who request records to guide them to the specific information they need based on their eventual use of the documents, Goethals says. Hiring a PHR patient liaison to work in the HIM department could be a patient-centric way to help guide patients to proper information requests.

The Health Information Bill of Rights

Patient rights were at the center of an initiative launched by AHIMA at its 2009 convention and exhibit. The Health Information Bill of Rights (HIBOR) serves both as an expression of health information rights for patients and a set of patient-centered principles for HIM professionals.

HIBOR lists seven rights and protections patients have with regards to their health information, including the right to access health information during the course of treatment and the right to a health record that is as complete and accurate as possible. The very first right stated is the right to access one's health information free of charge.

While HIBOR states patients should have "access" to records free of charge, some HIM professionals feel that patients should also get copies of their medical record for free.

Many facilities charge medical record copy fees as a way to offset labor and reproduction costs. But Mangin, a member of the blue-ribbon panel of accredited HIM professionals who wrote the bill of rights, says offering free copies of records is a way HIM departments can be more patient-centric.

"I'll have [a patient] walk in upset about something else-possibly a payer not wanting to cover their treatment-and when they ask you for their record and you tell them that there is a charge, they look at you like, 'You are going to charge me for my own information?'" Mangin says. "It is like the icing on the cake."

In order to enhance relationships, many HIM departments have begun offering free records to patients.

In 2005 Mangin's Good Samaritan Hospital started giving patients the first 10 pages of their record request for free. Many patients who request records just want an X-ray or lab work, and "it was just ridiculous to charge patients for three or four pages," Mangin says. At times the department has given completely free copies of records to Good Samaritan patients who said they could not afford copy fees.

Mangin recently submitted a proposal to hospital management to make all record copy requests free, regardless of their size. "I think it is time that we just got rid of that patient hurdle," she says.

Some HIM professionals are concerned that the HIBOR right to "access of your health information free of charge" could confuse patients who request their record and are met at some facilities with copy fees. While the print under the bolded "right" states that unconditional free access might not be offered by all facilities or under all state/federal laws, some feel patients will not understand the difference between the right to free access and free copies of their record.

Not all facilities can afford to offer completely free medical record copies, Mangin realizes. But HIM departments should at least make an effort to help those in special circumstances obtain copies of their record free of charge.

Another argument for offering free copies of records is that the process for release of information is on the cusp of radically changing, Mangin says. As facilities move to electronic records and processes, it will become much easier to reproduce patient records.

ARRA allows HIM departments to charge patients for reproducing a record, but the charge must be limited to the cost of the labor. As electronic systems advance, that cost should come down significantly, McGraw says. Use of direct patient portals into health records might even eliminate the need for a physical copy to be produced at all.

"I think the fees and processes we have had set up traditionally in the paper world for years are probably all going to have to be looked at," Mangin says.

HIBOR is not a law, and HIM departments choose to follow its provisions voluntarily. "But [the HIBOR panel] would like to think that HIM professionals would all work towards these rights and make them real in our own facilities," Mangin says.

The full bill of rights may be read in the AHIMA Body of Knowledge at www.ahima.org.

AHIMA Health Information Bill of Right

A Model for Protecting Americans' Health Information Principles

- The right to access your health information free of charge
- The right to access your health information during the course of treatment
- The right to expect that your health information is accurate and as complete as possible
- The right for you or your personal representative(s) to know who provides, accesses, and updates your health information, except as precluded by law or regulation
- The right to expect healthcare professionals and others with lawful access to your health information to be held accountable for violations of all privacy and security laws, policies, and procedures, including the sharing of user IDs and passwords
- The right to expect equivalent health information privacy and security protections to be available to all healthcare consumers regardless of state or geographic boundaries or the location (jurisdiction) of where the treatment occurs
- The right to the opportunity for private legal recourse in the event of a breach of one's health information that causes harm

Special Cases, Extra Attention

Becoming more patient-centric will not always require changes to operations or staffing. How HIM professionals interact with patients has a meaningful impact.

Many times, laws and policies prohibit HIM from granting patient requests. A mother, though she may pay her 19-year-old son's medical bills, does not have the right to access his medical records. When patient perceptions of their rights do not coincide with the law, HIM professionals can look like the bad guys.

Though HIM professionals might not be able to grant certain requests, the way they handle the refusals can mean the difference between an angry customer and an understanding one, Goethals notes. She tries not to stand behind policies and laws when she has to deny a request.

"Don't forget about the human factor in this," she says. "That is one thing I think sometimes we forget-that we are standing behind the wall, so to speak, and we say, 'Well, our policy says…' And okay, yes it does. And that is where the discussion needs to start. But let's all be advocates for the patient to help them get what they need."

Part of being patient-centric in HIM is being patient with patients, who can at times be upset or even distraught, Quinsey says. People can be in a dark place when they walk through the HIM doors. Death and illness may have wreaked havoc on their lives and the lives of their loved ones. The last thing many want to deal with is red tape or roadblocks that prevent them from what they feel is rightfully theirs.

HIM policies and procedures are instituted for a reason, and they should be followed. But sometimes being more patient-centric means that some special cases require extra attention.

"Some people's need for their record might be more urgent than others," Goethals says. "Hopefully, in 99 percent of the cases you can follow [your policies and procedures], and it is not an issue. But there may be a case here and there that you may have to take that personal touch and explain things a little bit more."

That’s where HIM professionals can step forward as patient advocates. When patients request their entire medical records, staff can take the time to ask what they need and why they are requesting their record, Goethals recommends. A person with 100 pages in their record may not need every page.

“Help them to get what they need,” Goethals says.

That step helps patients go home with the information they need, saves them potential copy fees, and spares HIM staff from compiling mounds of records that are not needed.

A New Interaction Emerging

For Mangin, the patient-centered movement and the changes to patient rights give HIM a unique opportunity to be an advocate for patients and their health information.

“I think the whole patient-centered movement is exciting, and it is good for us to have more interaction with patients,” Mangin says. “I think we are in a perfect role and it is an exciting time, versus maybe years ago when you were stuck in the basement and didn’t have any interaction with patients at all.”

Just how many patients will take advantage of these new rights is unknown. Many consumers may not be aware of the rights granted to them under state and federal law. It is not yet clear if ARRA will increase the amount of interaction HIM has with patients. But it certainly has the potential to, Roach says.

“I think there will certainly be some individuals who will take advantage of these new rights if they ever realize they have them,” Roach says. “[HIM] at least has to have a mechanism in place to interact with patients.”

However, while crowds of the “new patient” have not yet lined up requesting electronic copies of their records or special access restrictions, HIM will likely soon see an increase in patients interested in their records and how they are handled. “I think as time goes on we will see an increase in this, because people are getting a little bit more savvy,” Goethals says.

The laws are there. It is up to the patients to use them and HIM to honor them.

“The notion that we [HIM professionals] want to be patient-centric hasn’t changed,” Quinsey says. “How we do it has changed dramatically.”

Chris Dimick (chris.dimick@ahima.org) is staff writer for the *Journal of AHIMA*.

Article citation:
Dimick, Chris. "Empowered Patient: Preparing for a New Patient Interaction" *Journal of AHIMA* 81, no.2 (February 2010): 26-31.