

# Matter of Trust: Information Ownership and HIM's Role

Save to myBoK

by Linda Kloss, RRA, executive vice president/CEO

The *Journal of AHIMA* is honored to bring you a new landmark analysis of the age-old question "Who owns the medical record?" "Ownership of Health Information in the Information Age" rephrases and updates the question as "Who can do what to which data under what circumstances?" AHIMA receives a remarkable number of questions on the subject of ownership and the interest is growing, thanks to new technology and healthcare restructuring as well as new uses for and increasing value of patient information. Not only do authors Adele Waller and Oscar Alcantara update concepts and distinguish patient-identified and patient-identifiable data, they also provide advice on integrated delivery system contracts and contracts with information system vendors and clearinghouses.

## Our Nation's Patchwork of Law

Waller and Alcantara's article certainly illustrates the important differences in law and regulation from state to state, again calling into question why the US Congress seems unable/unwilling to take steps to protect the privacy of an individual's personal health information. Why is this not a pillar of our country's public policy as it is in many European countries? Steve Mathews describes the European Union's (EU) efforts to protect personal data, building on the strong laws that already exist in many countries in Europe. The EU laws will govern collection and processing of personal information and will impose strict standards on vendors and all who do business with or have access to health information—including US companies doing business in Europe.

We can hope for some transatlantic trickle-down that will encourage the US Congress to take this issue seriously at last. Attempts were made by the 104th Congress, and while we did not get legislation, the Health Insurance Portability and Accountability Act of 1996 set the stage for either a legislative or regulatory solution in the future. So far, the 105th Congress has been slow to pick up the ball. And even if legislation begins to work its way through the hearing processes, will supporters wield the power required to counteract opposition from powerful constituents? Attempts to enact legislation are moving forward slowly, and we can only hope that this will remain a priority with the likely sponsors.

## HIM as the de facto Trustee

I was struck by Waller and Alcantara's use of the word "trusteeship." *Black's Legal Dictionary* defines "trustee" in the broad sense as "anyone standing in a fiduciary or confidential relation to another, such as agent...." It seems to me that HIM professionals act (and feel the obligation to act) as the de facto agent for the patient on matters of privacy. This is not a new role—we have been studying and advancing practices for responsible information handling for seven decades. We have incorporated this role as a tenet in our code of ethics and the values of the AHIMA. We have issued policy and position statements, lobbied state legislators, resisted unauthorized intrusions, and tried to do battle with the Goliaths in Washington, DC.

Today we are like the little Dutch boy in a torrential rainstorm with his finger in the dike. Rivers of confidential information are flowing from our healthcare organizations almost unimpeded. Mountains of copies are made, and who knows where they end up? Why isn't there an uprising of indignation? Sadly, the cynics are probably right. It will take some kind of catastrophic information spill to get the attention of our legislators.

## Dikes and Levees for the Next Century

HIM professionals are building new technology and procedural infrastructures to carry out our trustee obligation to protect patient privacy rights. Eugene Carroll, Susan Wright, and Cindy Zakoworotny explain the fundamentals of securing remote access applications. AHIMA is actively developing training materials and practice guidelines in this area because information security practices will envelop yesterday's release of information practices. We are featuring our members, such as these

authors, to help everyone learn from leading-edge practice. And, of course, we are trying to get the legal and regulatory framework in place to help. We are keeping the trust, and we should be proud of ourselves.

As we neared press time, we received the Ethical Policy Statement on Health Information Confidentiality from the American College of Healthcare Executives (see below). We thought that you, the HIM trustee, should have this policy as it may help you to advance this issue in your own organization.

## **American College of Healthcare Executives' Ethical Policy Statement: Health Information Confidentiality**

### **Statement of the Issue**

Healthcare is among the most personal services rendered in our society; yet to deliver this care, scores of personnel must have access to intimate patient information. In order to receive appropriate patient care, patients must feel free to reveal personal information. In return, the healthcare provider must offer patients confidentiality.

However, maintaining confidentiality is becoming more difficult. Information systems technology allows instant retrieval of medical information, widening access to a greater number of people. Within healthcare organizations, personal information contained in medical records is reviewed not only by physicians and nurses, but also by professionals in many clinical and administrative support areas.

Healthcare executives must follow the laws governing release of information. Releases cannot be made without proper authorization. Healthcare executives must determine that patients or their legal representatives consented to the release of information.

Some exceptions to patient confidentiality are necessary—to promote public health, to protect children and spouses from abuse, and to comply with certain laws. Media representatives also seek access to health information, particularly when a patient is a public figure or treatment involves legal or public health issues. Nevertheless, the rights of individual patients must be protected. Society's need for information rarely outweighs the right of patients to confidentiality.

### **Policy Position**

The American College of Healthcare Executives believes that all healthcare executives have a moral and professional obligation to protect the confidentiality of patients' medical records. As patient advocates, executives must obtain proper patient authorization to release information or follow carefully defined policies on the release of information without consent.

While the healthcare organization owns the health record, the information in that record remains the patient's personal property. Organizations must determine the appropriateness of all requests for patient information and act accordingly.

In fulfilling their responsibilities, healthcare executives should seek to:

- Limit access to patient information to authorized individuals only.
- Ensure that institutional policies on confidentiality and release of information are consistent with regulations and laws.
- Educate healthcare personnel on confidentiality issues and take steps to ensure all healthcare personnel are aware of and understand their responsibilities to keep patient information confidential.
- Safeguard medical record files and computerized data with security and storage systems that provide against unauthorized access.

- Establish guidelines for masking patient identity in committee minutes and other working documents where the identity is not necessary.
- Ensure that policies concerning the right of patients to have access to their own medical records are clearly established and understood by appropriate staff.
- Create guidelines for securing necessary permissions for the release of medical information for research, education, utilization review, and other purposes.
- Adopt a specialized process to protect sensitive information such as psychiatric, HIV status, or substance abuse treatment records.
- Identify special situations that require consultation with senior management prior to release of information.
- When appropriate, seek written agreements that detail the obligations of confidentiality for individuals and agencies who receive medical records information.
- Collaborate with media representatives to develop procedures for the request of and release of medical information about patients in the public domain.
- Educate patients about organizational policies on confidentiality.
- Participate in the public dialogue on confidentiality issues such as employer use of healthcare information and public health reporting.

The American College of Healthcare Executives urges all healthcare executives to maintain an appropriate balance between the patient's right to confidentiality and the need to release information in the public's interest.

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