

# HIPAA—Providing New Opportunities for Collaboration<sup>1</sup>

**T**he date for compliance with the Health Insurance Portability and Accountability Act (HIPAA) was little more than a year ago, and hospitals and health systems are still engaged in extensive efforts to ensure they meet its requirements. While the job they face is daunting, it is helpful to recognize that HIPAA creates new and positive opportunities for health care providers, as well as a myriad of legal requirements. HIPAA's focus on patients' rights to confidentiality and to access to information has created an environment that can facilitate and support collaboration among patients, families, and health care providers. It has raised national awareness and brought to the fore many issues of longstanding importance to practitioners of patient- and family-centered care.

As implementation of HIPAA moves forward, it is critical to build on those areas where the principles of patient- and family-centered care and HIPAA priorities are mutually supportive. These areas also need to be acknowledged and built into training programs so that administrators and staff better understand how HIPAA should be applied in everyday practice. Practitioners committed to patient- and family-centered care can take advantage of the momentum provided by HIPAA in many areas and work toward shared goals.

This article summarizes HIPAA "basics." It defines its key terms and describes patient rights and protections under HIPAA. It then offers an

in-depth discussion of specific issues relating to the interface of HIPAA and the principles of patient- and family-centered care.

## Background and History of HIPAA

The U.S. Congress enacted the Administrative Simplification Provisions of the Health Insurance Portability and Accountability Act of 1996 to facilitate the transformation of the health care delivery system into the information age. The HIPAA privacy regulations took effect on April 14, 2001, and the compliance date was April 14, 2003. The regulations ensure a national floor of privacy protections for patients by limiting the ways in which health plans, pharmacies, hospitals, and other entities can use patients' personal medical information. The regulations protect medical records and other individually identifiable health information, whether it is written on paper, transmitted electronically, or communicated orally.

One of HIPAA's original purposes was to help patients retain access to health benefits by allowing them to take their insurance with them when they moved from one job to another (hence the word "portability" in its title). As the HIPAA legislation was being drafted, supporters saw it as an opportunity to take on a broader charge—to make health care more "effective and efficient," especially with respect

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to documentation and reimbursement. Part of the administrative simplification mandated by HIPAA, legislators decided, would be the development of a standard set of data that all insurance companies could use for purposes of reimbursement. Those data were to be available through electronic transfer.

Concerned that broad use of electronic technology could erode the privacy of health information, Congress incorporated into HIPAA provisions that mandate the use of federal privacy protections for individually identifiable patient health information. HIPAA is the first federal legislation to articulate a set of basic expectations around individual privacy.

### The Health System Responds to HIPAA

As health care providers and administrators moved forward to comply with the privacy regulations portion of HIPAA, they often found themselves in unfamiliar territory. They engaged in major training efforts; many hired consultants to help them interpret and implement the law. Nonetheless, many organizations are still struggling to interpret its provisions correctly and to comply with its wording as well as its intent.

Unfortunately, the desire to comply with HIPAA has led some hospitals to inadvertently create unnecessary barriers to patient- and family-centered approaches to care. For example, in some ambulatory settings, patients are now asked to take a number in the waiting area, and they are called for their appointments by number, rather than name, which is a dehumanizing experience. In other settings, staff have reverted to the depersonalizing practice of referring to the patient as, for example, “the gallbladder in room 406,” rather than by name. Some hospitals have curtailed family member presence in critical care or perioperative settings. Concerned that confidential patient information might inadvertently be heard by non-family members, some physicians and nurses are questioning the legality of family and patient participation in rounds. The participation of patient and family advisors on hospital committees, where sensitive patient-related matters are discussed, has likewise been questioned and,

in some cases, cut back or restricted.

Such decisions reflect an inadequate understanding of HIPAA’s intent. Rather than being used as a pretext for erecting barriers to patient and family participation in care, HIPAA legislation can be seen in a supportive light. HIPAA requirements concerning documentation and communication, for example, can be construed as an indication of new support of principles of information sharing that are essential to patient- and family-centered care.

Correct interpretation of this complex law requires, first of all, an understanding of its key terms. Many of the more important of these terms are defined in the following section. For more information, readers may wish to visit the HIPAA Web site: [www.hhs.gov/ocr/hipaa](http://www.hhs.gov/ocr/hipaa).

### HIPAA Glossary

**Protected health information.** Protected health information (PHI) is any information about a patient that is linked with a piece of demographic information (for example, name, birth date, or medical record number) that might identify that patient. A diagnosis that has no name attached may not always be PHI; however, a patient’s name, even if it has no accompanying diagnosis, is PHI.

Prior to HIPAA, people generally did not view demographic data as private (although they did respect the privacy of medical information). Now, whenever medical information and demographic information are linked, they are considered PHI. Such information is termed “individually identifiable” and therefore subject to HIPAA.

**Minimum necessary.** Health providers may use and disclose minimum necessary information, that is, only the information they absolutely need, to its organization’s workforce or to external requestors. That minimum is defined on the basis of individual circumstances. For example, if a patient’s age is irrelevant to a given situation, then the provider should not disclose it. If an agency does not need to know a diagnosis, it should not receive any information about it.

PHI can be used and disclosed for three primary reasons: treatment, payment, and health care operations. Within a system, there

is no minimum necessary when it comes to treatment. Issues relating to minimum necessary are less restricted with respect to members of the treatment team than they are for other employees of a hospital, clinic, or other type of health care agency. But even from an internal perspective, health systems need to look carefully at what information is available and to whom. This entails examining the information needs of varying classifications of employees. For example, housekeeping staff need to know what precautions to take when they clean a patient room, but do not need information about the diagnosis or treatment of the patient.

**Disclosure.** A disclosure occurs any time that a health system or a health provider releases information about a patient to someone else. HIPAA requires that health organizations monitor disclosures and that they be able to tell patients when and with whom their PHI has been shared.

In certain situations, a disclosure is mandatory. The justification for such disclosure is usually the benefit of the public at large, and it is often state-specific. The operative principle is that if disclosure is mandatory under a state or another federal law, it is allowable under HIPAA. In Illinois for example, if a police officer apprehends a driver who has been injured in a crash and accompanies that person to the emergency room, the officer has the right to request information on the driver's blood alcohol level, on the basis of the possibility that the driver was driving while intoxicated. According to Illinois regulations, ER staff are legally bound to give the results of blood alcohol tests to the police in this situation. These mandatory disclosures must be included in the accounting of disclosures that is available to a patient.

**Authorization.** An authorization is a patient's signed agreement for a disclosure. If a health care provider wants to make a disclosure of PHI that is not allowed by HIPAA requirements, the patient has a right to know of this intention and must sign a document giving consent to it. In addition, patients must sign a specific authorization even if the disclosure is at their request, for example, for release of their medical information to a requesting agency such as an insurance company or law firm.

Disclosure requirements have a strong impact on clinical research. Most clinical investigations involve the disclosure of subjects' health care information in order to enable researchers to evaluate and use the study results. Institutional review boards (IRBs) are responsible for maintaining the balance between scientific integrity and human research subject protections, including HIPAA privacy and security protections. Investigators must submit research protocols and informed consents that detail data collection and data use for IRB review and approval. Specific subject authorization can be waived only in certain cases, and only with the review and approval of the IRB.

**Notice of Privacy Practices.** HIPAA requires that every health care provider and insurance carrier provide a Notice of Privacy Practices to patients. This notice must tell patients how the hospital or health agency needs to use personal medical information and describe the patient's rights. The provider must provide a copy of this notice to the patient the first time he or she enters a system. Moreover, that notice should be posted in prominent locations throughout the organization. It should certainly appear at the entrances to health facilities; many agencies or systems also post the notice on their Web sites. A health system's legal counsel should approve the organization's Notice of Privacy Practices.

The law poses requirements concerning the format of the notice. For example, they must be printed in sufficiently large type, and they must use "plain language." In other words, the notice needs to be understandable to the population served.

### Patient Rights and Protections under HIPAA

HIPAA provides specific patient rights. From the perspective of patient- and family-centered care, the most important of these rights are the following:

**Access to medical records.** While many states have established provisions for patient access to medical records, HIPAA is the first nationwide legislation that guarantees patients' access to these records. The health care entity must respond to such a request within 30 days.

**Case Example: Requesting an Amendment**

A long-time patient of Hospital X had been diagnosed with seizures and had been successfully treated for the condition about 10 years ago. She had not had a seizure since that time, and she was no longer on seizure medication; however, her medical record still carried a primary diagnosis of seizure disorder. The woman made a written request that the hospital amend her record, deleting seizure disorder from the current list of conditions, because she was having difficulty obtaining health insurance.

The privacy officer met with her physicians, and they agreed that this was no longer a primary diagnosis. After review, the hospital team concurred. The record was amended. HIPAA regulations made this case possible—the woman was granted access to her records and requested a justifiable amendment.

The patient also has a right to request a copy of his or her medical record.

**Request for amendments.** If a patient does not agree with the medical record or thinks that the information is incomplete or inaccurate, he or she has the right to request that it be amended. The health system must respond to the patient’s request for amendment, but does have the ability to deny such a request. For example, a patient might question or protest a diagnosis, say, of clinical depression. But only if the physician agrees will the diagnosis be changed. The patient’s amendment request, however, goes into his or her medical record.

**Request for restrictions.** Beyond the restrictions guaranteed for the protection of PHI, a patient may request specific additional restrictions that will ensure the confidentiality of private information. A patient may, for example, request limitations on how information will be disclosed to family or friends involved in their care. The patient may request a restriction on the use or disclosure of data for treatment, payment, and health care operations. In the absence of such a restriction, the hospital can disclose such information and does not need to request the patient’s permission.

**Confidential communication.** Patients may ask their doctors, health plans, and other entities to take reasonable steps to ensure that communi-

cations are kept private. For example, a patient may request that confidential information not be mailed to his or her home, or that recorded voice-mail messages not be left at their home or place of employment. If the request can be reasonably accommodated, the provider must do so.

**Disclosure accounting.** Under HIPAA, each time a health system, provider, or third-party payer discloses information, other than for treatment, payment, or health care operations, it must keep a record of that disclosure. This is true for any disclosure, including those that are legally required, except when a patient has signed a specific authorization. For example, when a patient is being treated for SARS, the staff must make the appropriate documentation in the organization’s accounting of disclosure log upon reporting the diagnosis to the Centers for Disease Control and Prevention (CDC).

A patient has the right to request a list of all such disclosures entered in his or her medical record for up to six years. (Information for disclosures made before the date of mandatory compliance with this law, April 14, 2003, is not covered.)

**Right to complain.** Patients who believe their privacy has been violated have the right to complain—not just to the individual appointed by the hospital to hear such complaints but also to the Office of Civil Rights of the U.S. Department of Health and Human Services. The fact that patients have such recourse is a strong indication of the government’s desire to ensure that hospitals and other health care entities are responsive to patient concerns.

**Independent and Shared Domains**

HIPAA and patient- and family-centered care share the following objectives:

- to restore and strengthen trust among patients, families, and health care professionals;
- to enhance patient rights;
- to improve the efficiency and effectiveness of care; and
- to enhance the patient’s experience of care.

Other areas of common purpose are shown in Table 1.

The difference between HIPAA and patient- and family-centered care relates more to approach than to philosophy or intent. HIPAA is concerned with privacy and security of patient information. Maintaining privacy entails setting boundaries that govern how such information is used and to whom it is released. HIPAA emphasizes accountability and sets forth legal penalties for those who fail to comply. HIPAA is also concerned with balancing the patient’s right to privacy with public responsibility. To protect the public interest, HIPAA permits the release of certain types of patient information to the police department, state public health officials, or public agencies such as the CDC.

Like patient- and family-centered care, HIPAA focuses on giving consumers more control over their care. It supports patient and family involvement in the planning and delivery of care. And, because a consumer cannot be in control of care unless he or she is well informed, both HIPAA and patient- and family-centered care emphasize information sharing.

Patient- and family-centered care fosters mutually respectful partnerships where there is open and honest communication. This leads to an informed patient—one who assumes control of his or her care. The provider, instead of imparting facts and information to the patient and family, engages in a dialogue.

### Need for Flexibility and Transparency

Hospital administrators and staff who wish to comply with HIPAA in a way that is synergistic with patient- and family-centered approaches need to understand that the law does allow room for flexibility and professional judgment. The regulations do not impose a “one-size-fits-all” structure that governs patient care. Patients and their families have the right to decide who will be involved in their care. They even have the right to define the word “family.” The way in which this option will be exercised should be defined in the hospital’s policy and stated in the treatment plan.

A second word that is of the essence to both HIPAA and patient- and family-centered care

**Table 1: Purposes of HIPAA and of Patient- and Family-Centered Care**

HIPAA	Patient- and Family-Centered Care
Protect and enhance patient rights relating to access to information and the use of PHI.	Promote the view that the patient and, if the patient wishes, the family, are integral members of the health care team.  Encourage participation in information-sharing regarding care planning and decision-making.
Improve health care quality by restoring trust.	Enhance the quality and outcomes of patient care.  Promote collaborative, empowering relationships among patients, families, and caregivers.
Improve health care efficiency and effectiveness through a nationwide framework.	Enhance the patient’s and family’s experience of care.

is transparency. In defining this concept, the Institute of Medicine report *Crossing the Quality Chasm: A New Health Care System for the 21st Century* states that “the health care system should make information available to patients and their families that allows them to make informed decisions when selecting a health plan, hospital, or clinical practice, or choosing among alternative treatments” (2001, p. 62).

Transparency demands clarity in each patient’s care plan. It also requires clarity in the rationale and decision-making process supporting that plan on the part of all involved—the patient, family, health care professionals, trainees, and students. With this shared understanding and openness in communication, there is greater opportunity to collaborate in ensuring the quality and safety of care.

Transparency demands not only that the patient have access to information but that it be expressed in an understandable way. The use of clear language, mandated by HIPAA, is essential. The best way to ensure readability is to have representatives of the target audiences

participate in drafting and reviewing all written information that may be shared with or seen by patients and families. For example, patients and families can assist in developing and refining the language and format for a hospital's Notice of Privacy Practices (see above), just as they do in creating other patient and family information and educational materials.

### Specific Issues

Presented here are some of the issues of concern to hospitals with respect to HIPAA and examples of how some institutions have responded in ways that are consistent with principles of patient- and family-centered care.

### Setting the Tone

It is important that patients, family members, and visitors understand an institution's commitment to privacy. This can be done in individual conversations with staff, but announcing the policy in a more formal way is also helpful. In order to create an environment that is respectful of patient privacy, MCG Health, Inc. in Augusta, Georgia, has signs within its hospitals and clinics stating, "In conversation, please respect patient privacy."

### Patient Identity/Information Boards

Immediately after HIPAA became effective, some health care facilities took down their patient identity/information boards. In some circumstances, this was necessary. For instance, an academic medical center had mounted a patient identity/information board in a room adjacent to the main entrance of the hospital. The board listed names of patients with tumors who were awaiting pathology review. The names were visible to anyone entering the hospital. This practice did not protect an individual's privacy, and the hospital correctly moved the board to another location.

On the other hand, identity/information boards in clinical areas may be necessary to the provision of safe and effective care. For example, another medical center decided to keep a patient identity/information board at the

nurses' station in the preoperative admissions and prep area of its surgical suite. While there was a risk of incidental exposure if a family member approached the desk and viewed the information, there was a greater risk to patient safety and quality of care if the surgery and anesthesia staff did not have immediate access to updated patient data. The board was maintained, but using modified patient information (that is, last name and initial of first name).

### Charts and Other Documentation

Many hospitals locked up patient charts and removed them from the bedside when HIPAA became effective. This may not be necessary and could inhibit the sharing of information important to patient care. A reasoned approach is to provide a cover for the chart, but to keep it accessible to the patient, family, and other members of the care team.

For further information about charting and documentation, see the articles beginning on pages 12, 20, 21, 22, and 26 in this issue of *Advances*.

### Discharge Reports

Discharge and ambulatory care summary reports are important to quality care. Frequently these reports need to be shared with the patient, family, and hospital- and community-based providers. At the Children's Hospital at Dartmouth in New Hampshire, reports evaluating children with neurodevelopmental and behavioral problems originate in the ambulatory care clinic. These reports contain findings regarding the child and family and the community situation. A draft of the report is sent to the family for review and comment. The final report is then sent to the parents, and they are asked to disseminate it to community providers and agencies of their choice. In this manner, parents are involved in developing the report and have control over how this information is shared.

### Patient and Family Participation in Rounds

With growing understanding of patient- and family-centered practices and the importance

of including the patient and, if the patient wishes, the family, in care planning and decision-making, more and more hospitals are inviting patient and family participation in rounds. Most of these hospitals balance the risk of disclosures of protected health information against the improved quality of care that emerges from patient and family participation in rounds. These hospitals realize that informed and engaged patients and families can be allies in ensuring patient safety. Participation in rounds is one of the ways through which family members can become knowledgeable about medications, treatments, and early signs of problems or changes in health status. The concept of “nothing about me without me”<sup>2</sup> truly becomes a reality when patients and families and others on the health care team work together in the rounding process. In academic medical centers, where rounds have an important teaching function, the active participation of patients and families provides an opportunity to model effective communication for students and trainees.

Potential problems relating to confidentiality and rounds are fewer in hospitals that offer private rooms to all patients. Currently, most hospitals in the United States have both single and multibed rooms. If there are no other options, it is generally better to discuss confidential matters even in a semiprivate or multibed room than in a hallway, where the possibility of being overheard and of violating confidentiality are much greater.

Establishing the importance of maintaining confidentiality and privacy with patients and families as part of preadmission orientation or admission procedures can be instrumental in implementing HIPAA. If patients and families understand the measures that hospital staff take and the ways in which they can assist, then they can become strong partners in helping to protect their confidentiality.

Changes in the physical facility, such as the use of acoustic ceiling tiles, carpeting, and thoughtful placement of walls, can reduce

### Confidentiality Statement at Dartmouth

The Intensive Care Nursery at Children’s Hospital at Dartmouth is piloting a Confidentiality Statement that parents are asked to sign shortly after their child’s admission. This statement, developed collaboratively by staff, faculty, and families, reinforces the belief that parents are valued members of the health care team and encourages them to be actively involved in the care and treatment of their infant, including participation in rounds. Since the unit is a multibed unit, families may hear bedside conversations about other infants and families. They also may overhear conversations in the family lounge or in overnight facilities for families served by the hospital. By signing the Confidentiality Statement, families agree not to share information about other infants that they may overhear during their infant’s hospital stay.

noise levels, so that rounds can be conducted more quietly. Hospital staff and patient and family advisors may also conduct privacy walk-throughs, during which they focus on how private information might unintentionally be disclosed. They then can plan appropriate precautionary measures. Simple measures, such as asking staff to lower voice levels when possible and putting screens over desktop computer monitors in the areas that family members and visitors enter are reasonable.

All health care facilities should include information about the hospital policy regarding patient and family participation in rounds on their routine consent form. This provides an opportunity to encourage patients and families to take an active role in their health care and to tell them of the possibility of incidental disclosures. It also underscores the hospital’s sensitivity to this possibility and to the measures it is taking to prevent inadvertent disclosure of private information.

### The Surgical Experience

Practices are beginning to change for the surgical experience, with the goal of minimizing the amount of time a patient is separated

<sup>2</sup> This phrase, first articulated by an English midwife at a Salzburg seminar in 1998, has since been adopted by leading health care authors. It is cited in *Crossing the Quality Chasm: A New Health System for the 21<sup>st</sup> Century*, published by the Institute of Medicine in 2001. Source: National Patient Safety Foundation’s “National Agenda for Action: Patients and Families in Patient Safety—*Nothing About Me, Without Me.*”

from his or her family. Some family members may wish to remain with the patient through as many stages of the entire surgical experience as possible, including awaiting surgery in a holding area or hallway, induction, and postanesthesia care. Quality improvement studies have documented the benefits of family member presence at such times (Fina et al., 1997; Tuller et al., 1997). For example, studies of both pediatric and adult postanesthesia care have shown that when family members are present, patients are less restless and require less medication. Patients and families report greater satisfaction with care, and nurses report greater satisfaction with their professional practice.

The areas in which these activities take place, however, are not always private, and this may raise staff concerns about HIPAA violations. Again, the option for families to remain present should be defined as part of hospital operations and the treatment plan. Families and patients can be informed of the option to remain with the patient in written, audiovisual, and Web-based materials. Information about the need to respect a patient's privacy and suggestions for how to do so can be included in preoperative materials, as can information on to support a surgical patient. Patients who have experienced surgery and their families should participate in the development of these materials and ensure that they contain relevant and practical information.

### Emergency Care

Perhaps nowhere is the need for exercising professional judgment and flexibility more important than in emergency care, where deci-

sions in the patient's interest must be made quickly. Ordinary procedures that govern such issues as disclosure of health information under normal circumstances, for example, may often need to be interpreted differently when a patient is dying or unconscious.

Whenever possible, it is essential that the patients not be separated from family members during emergency care, just as they should not be separated during any other type of health care experience. Nonetheless, patients often arrive in an emergency room alone; no family members accompany them. Staff must make a good faith effort to identify patient's family members and to inform them of the situation. The need for information at this time is, of course, a two-way street: family members can also be a vital source of information necessary to proceed with appropriate treatment. In such situations, information may need to be disclosed over the phone for the care and safety of the patient. Staff are expected to take reasonable steps to verify identity of the individual on the phone.

Finally, given the crucial situations that are common in an emergency, HIPAA makes allowances for health care providers to use their professional judgment when making a disclosure or in other ways dealing with PHI. For example, providers may need to include family in a discussion, answer questions when visitors may be in the room, or engage in other necessary activities.

### Peer Support

The benefits of peer support for patients and families are well documented in the literature (Singer et al, 1999; Lorig et al., 2001; and Lorig and Holman, 2003); however, some health care professionals believe they cannot connect patients and families with others who have had similar experiences because it would violate confidentiality. This concern can be overcome simply by asking the patient or family whether they wish to have their name shared with others for peer support. A notation of the patient's wishes can then be made in the chart. A signed permission form is not necessary. Information about HIPAA should be included in the training of those who provide peer support.

#### Peer Support at MCG Health, Inc.

At MCG Health, Inc., patient support group participants are asked to indicate if they are willing to be a "buddy" or to be assigned as a "buddy" to a group member with a similar diagnosis. In addition, MCG has modified some procedures for bereavement support meetings and memorial services to accommodate family participation within HIPAA. For example, letters are sent to families asking if they wish to participate in the Children's Medical Center memorial service. At the service the family lights a candle and speaks the child's name (if they wish), and may share photos in memory of their loved one.

## Hospice Care

Hospice care is an area where the need for professional judgment may be particularly critical. If a patient who is terminally ill has no family in the immediate area, for example, it is often in the patient's interest to permit the disclosure of otherwise confidential information to a trusted friend or other individuals who are not members of the immediate family. Under ideal conditions, the patient would give permission for information to be shared with these persons, and a notation would be made in the chart. If the patient is not capable of giving this permission, however, the provider must, on the basis of his experience and understanding, make an individualized decision concerning information sharing that will avoid isolating the patient from his or her natural support network.

## Family and Patient Participation on Hospital Committees and Councils

In light of HIPAA and its emphasis on respecting patient privacy, many hospitals have expressed concern about the substantive involvement of patients and families in various advisory councils and other hospital committees, such as those that deal with quality, patient safety, or risk management. Members of these committees have a legitimate reason to see patient data in the course of their work.

A key way to ensure compliance with HIPAA is to make sure that all members of such committees—patients and family members, as well as staff—undergo HIPAA workforce training.

Some hospitals carry out such training under the aegis of their volunteer services departments. It is also advisable to have a health care provider speak with each potential council or committee member in advance and to explain HIPAA privacy regulations and their obligations, should they become a patient or family advisor.

At Dana-Farber Cancer Institute, patient and family advisors receive HIPAA training. They are full members of many committees, including the board-level Quality and Risk Management Committee. They participate fully in the discussion of root cause analysis

findings from event investigation of errors and near misses. Hospital leaders report that patients and families advisors readily understand the importance of safeguarding confidentiality of information and do not pose a risk of breaches of confidentiality.

## Education and Training of Health Professionals

Just as hospitals are conducting inservice trainings to inform current staff about HIPAA, they must also build such training into educational programs for health professionals in training. The sharing of PHI is an essential component of the educational experiences for students and trainees in the health professions in hospitals and their affiliated community programs. HIPAA is in no way intended to interfere with this information-sharing process. At the same time, to ensure compliance with HIPAA, students, trainees, and faculty must be informed about policies related to patient information, privacy, and security and be held accountable for upholding them.

Staff, students, trainees, and faculty must also be trained in and held accountable for practicing patient- and family-centered care (i.e., the importance of conveying respect to the patient and family, sharing complete and unbiased information in a supportive manner, and collaborating with the patient and family and encouraging their participation as members of the health care team) and be helped to appreciate the ways in which it is consistent with HIPAA.

## New Opportunities for Collaboration

Patients and families bring important perspectives to the implementation of HIPAA. They can participate on committees and task forces. They can assist with the Notice of Privacy Practices—how it is communicated, formatted, posted, and distributed. Patients and families can be partners in training efforts related to HIPAA. They can help staff, students, and trainees understand the importance of privacy and confidentiality, access to the medical record, and participation in decision-making and what these practices truly mean in people's lives.

As providers become more comfortable with HIPAA, they may identify ways to use it to further improve care. For example, saying that patients may see, or request amendments to, their medical records is commendable. But it would be even more productive to encourage them to become involved in the development of their record from the beginning. This would require building the system's capacity to gather patients' (and families') input in an ongoing manner.

As hospitals and other health care organizations gain increasing experience with integrating patient- and family-centered concepts with the implementation of HIPAA, they will undoubtedly find new synergies between these two areas and develop effective strategies for protecting privacy and ensuring appropriate access to information. The Institute for Family-Centered Care's Web site's "Let's Talk" section ([www.familycenteredcare.org](http://www.familycenteredcare.org)) offers a forum for the sharing of experiences with many of the issues described in this article.

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