
Understanding Patient Confidentiality and Health Information Tracking – An Overview

by Ronald Domen

Confidentiality is fundamental to medical practice and one of the oldest principles of medical ethics. Yet the need to track health care information and the sheer number of individuals who now have electronic access to medical records makes it increasingly difficult for physicians to claim exclusive control of their patients' information. This article reviews the literature and the importance of confidentiality as a guide for clinicians. It suggests that accurate, timely, and complete records must not only be available; they must also be maintained in a secure system, as medical confidentiality becomes everyone's responsibility.

We live in an information age. The demand for health care information is no exception, as almost logarithmic increases have been observed in the number of individuals demanding access to a patient's medical record. The need to track health care information for outcomes reporting and research, benchmarking, quality assurance, scientific research, billing and collection activities, and regulatory requirements helps fuel the demand for access to the medical record. A great number of individuals, groups, and organizations will, of necessity, have access to any individual patient's health information. The efficient collection, handling, transmission, and storage of this vast amount of information can only be achieved through electronic means. The halcyon days of protecting a single copy of the patient's medical record in a single location are gone, and it is increasingly difficult for physicians to claim exclusive control of their patients' medical information.

The Importance of Confidentiality

Confidentiality is fundamental to medical practice and one of the oldest principles of medical ethics. This basic principle first appeared in the Hippocratic Oath and remains an essential element of the physician-patient relationship.

Medical Codes of Ethics from sources as diverse as the Declaration of Geneva, the American Medical Association, and World Medical Association, all support the concepts underlying medical confidentiality (Fig. 1).

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The issue of confidentiality is gaining in public recognition and importance. A 1995 Harris poll found that 82 percent of people were concerned about their privacy, including the privacy of their medical records, compared with 64 percent in 1978. And a 1993 Harris poll found that a majority of the public — 56 percent — favored the enactment of strong federal laws to protect the privacy of medical

Hippocratic Oath (4th Century B.C.E.)	<i>"Whatever in connection with my professional practice, or not in connection with it, I see or hear, in the life of men, which ought not to be spoken of abroad, I will not divulge, as reckoning that all such should be kept secret."</i>
Percival's Code of Medical Ethics (1803)	<i>"Patients should be interrogated concerning their complaints in a tone of voice which cannot be overheard."</i>
American Medical Association (1847)	The AMA's first Code of Ethics, a revision of Percival's work, formally included the principle of confidentiality. Patients <i>"should never be afraid"</i> to make physicians their friends and advisors, but always bear in mind that medical persons are <i>"under the strongest obligation of secrecy."</i>
The Declaration of Geneva (1949)	<i>"I will respect the secrets which are confided in me, even after the patient has died."</i>
The Declaration of Helsinki (1975)	<i>"Concern for the interests of the subject must always prevail over the interest of science and society."</i>

Figure 1. – Confidentiality in Medical Codes of Ethics (after Razis 1990)

information. Data from the University of Texas Medical Branch – Galveston presented in the April 1998 issue of *Medical Ethics Advisor* identified patient confidentiality as one of the top five bioethical issues coming before their ethics committee (Anonymous 1998).

A recent article defines the terms *privacy*, *confidentiality*, and *security* (Gostin et al. 1993). *Privacy* is an individual's right to limit access by others to personal information. Informational privacy puts that information about a person beyond the range of others' knowledge without specific authorization. *Confidentiality* is a form of informational privacy characterized by a special relationship, such as the physician-patient relationship. Personal information obtained during the course of the physician-patient relationship should not be revealed to others without the patient's consent. *Security* entails a set of technical and administrative procedures that are designed to protect data systems against unwarranted disclosure, modification, or destruction. These procedures safeguard the system itself.

Ethical Justifications

The ethical justification for privacy and confidentiality is closely tied to the principle of autonomy. To respect a patient's privacy and confidentiality is to respect his or her wish not to have personal information made available to others. In this regard, privacy and confidentiality may not be treated as a commodity to be sold or traded for efficiency or to achieve cost-effectiveness in the health care system. It is, rather, a value that needs protection. Moral arguments for confidentiality are also rooted in principles of utility and duty. Utilitarians argue that breaching confidentiality weakens society's faith in the greater institution of medicine and threatens the physician's ability to gain detailed and accurate medical information. But accurate information is necessary for correct diagnosis and proper treatment; hence, the duty or obligation to uphold the patient's right to confidentiality.

Confidentiality and respect for privacy enhance the development and maintenance of intimate human relationships, the very core of the physician-patient relationship. Without the assurance of

confidentiality — and the trust, friendship, and respect that it engenders — people may be less forthcoming with medically relevant information, and such reticence can adversely affect both the individual and society. The duty of confidentiality serves a critical function in the physician-patient relationship. It encourages the patient to disclose all information that is relevant to his or her medical record. A breach of confidentiality can alter the physician-patient relationship from a sense of trust to a sense of betrayal. Maintaining confidentiality encourages patients to seek medical care, fosters trust in the physician-patient relationship, prevents discrimination based on illness, respects patient privacy, and is expected by patients (Lo 1995).

Informational confidentiality is also ethically justified to guard against a variety of adverse effects should unwarranted breaches occur. For example, economic harm, such as loss of employment or employability, insurance or insurability, or housing could occur as well as social or psychological harm.

Some, of course, think that the principle of confidentiality as espoused by many patients and physicians no longer exists (Siegler 1982). Changes in the delivery of medical services and the increased access to the medical record by many health care teams and individuals makes confidentiality irrelevant, impossible, and anachronistic. I propose, however, that even in today's high-tech, multidisciplinary team approach to medical care, the sanctity and trust underlying the physician-patient relationship remains the bottom line.

Breaches in Confidentiality

Confidentiality, like many other ethical duties, is not absolute and can be overridden. For example, patient confidentiality is justifiably breached in a few instances as required by law (e.g., in cases of infectious disease or child abuse). These instances protect the welfare of innocent others in a potentially harmful situation. But even in these situations, the physician should make every effort to discuss the mandate with the patient so that any necessary breach in confidentiality can be

performed with minimal harm to the patient. Lo (1995) summarizes situations in which the overriding of confidentiality may be warranted. They include one or more of the following conditions:

- the potential harm to third parties is serious,
- the likelihood of harm is high,
- no alternative means exists to warn or protect those at risk,
- the third party can take steps to prevent harm, or
- the harms resulting from the breach of confidentiality are minimal and acceptable.

It is always possible however, that justified breaches in confidentiality will result in further breaches — or lead to medically undesirable side effects. For example, recent policies mandate HIV and drug testing for pregnant women and newborns. That pregnant patients faced with this breach of confidence may choose to delay or avoid any contact with the health care system is clear from actual events in South Carolina. There the rate of women delivering babies in abandoned buildings and bus stations increased dramatically following the implementation of a mandatory prenatal drug screening policy with criminal sanctions for women who test positive (Oberman 1998).

In 1997, for example, the South Carolina Supreme Court upheld the conviction of a woman who was sentenced to eight years in prison for taking drugs (cocaine) while pregnant. At birth, the baby's blood tested positive for cocaine. The Court ruled that a viable fetus is covered by the state's child abuse and neglect laws (ACLU 1997). Mandatory HIV testing of pregnant patients may, for the same reasons, deter some patients from seeking and obtaining medical services (Cooper 1997).

Physicians and other health care professionals must be vigilant and knowledgeable in how federal or state governments operate to reestablish the legal boundaries of the duty of confidentiality in the

physician-patient relationship. Otherwise, physicians could find themselves working against, rather than with, their patients. Such an adversarial posture is unproductive; it does not promote the health and well-being of patients, pregnant or otherwise, and may exacerbate many of the underlying problems that led to its adoption.

The care of adolescent patients also involves problems related to confidentiality. Family support may be critical or even necessary in an individual case, but it must also be balanced with the adolescent's right to confidentiality and decision-making autonomy. This balance is especially precarious in situations involving birth control and contraception, sex education, and reproductive rights. Legal mandates to force adolescents and their physicians to disclose requests for birth control, for example, are likely to result in fewer requests for birth control rather than any decline in teen-age sexual activity. In such cases, physicians need to be knowledgeable about "emancipated minor" laws and other state laws concerning the right of adolescent patients to confidentiality.

Another problem arises when the treating physician is also the physician for the company or organization in which the patient is employed, or when information is requested by the company's physician. In such situations, the physician may be responsible to both the employer and the employee/patient. The necessity for informed consent prior to the release of any information is paramount, and only that information which is specifically authorized for release by the patient should be disclosed. If special rules or regulations exist concerning the limits of confidentiality (e.g., in government or military agencies), physicians should remind each patient of these special rules before commencing treatment.

The increasing role of third parties means that physicians are often accountable to individuals and organizations with interests that may be peripheral to those of the patient and not always in the patient's best interests. Such third parties include tumor and disease registries; insurance companies' or managed care organizations'

databases; research programs; government-sponsored health programs; pharmacy networks; disease foundation databases and mailing lists; federal and state legislative efforts; and public health databases and registries — a seemingly endless source of trafficking in, and control of, confidential health information.

Safeguarding Medical Records

Gostin et al. (1993) have proposed a way to enhance and ensure some measure of informational privacy and confidentiality at the national level. They call for establishing

- national privacy safeguards (through federal legislation),
- a system of universal (unique) identifiers for the health care system,
- effective (nonvoluntary) security standards and guidance for health care information,
- a data protection system and security panels for overseeing privacy and security, and
- a comprehensive program for fostering privacy and security education and awareness.

As various approaches to maintaining medical confidentiality and privacy in an electronic era are discussed and researched, standards will be established, security systems for computers will be developed and installed, and state and federal regulations will be mandated. The 105th Congress circulated at least two bills dealing with medical privacy and confidentiality: the Bennett-Jeffords bill and the Leahy-Kennedy bill, and one or the other is likely to be revisited by the 106th Congress.

These initiatives notwithstanding, the most important safeguard to medical confidentiality continues to rest on long-held traditions in ethics and professional conduct. Moreover, in our current information age, the obligation to respect confidentiality in the physician-patient relationship must be extended to, and be instilled in, everyone who has access to the patient's personal health record. Such respect for patient confidentiality extends to conversations in public places such as hallways and elevators, in the

handling of patient reports through telephone and fax transmissions, and in ensuring proper informed consent before information is released to a third party. Not only physicians, but all health care workers need to be vigilant of the increased risk for invading patients' privacy, and should work for ways to help ensure confidentiality. Physicians are still in the best position to act as advocates to secure the confidentiality of patient records within their respective institutions. However, it is increasingly clear that privacy and confidentiality should also become part of the hospital's organizational, or business, goals and codes of ethics.

In summary, respect for confidentiality is a strong ethical tradition in medicine that continues to garner a great deal of interest and support from patients and all who are directly involved in patient care. Individuals have a fundamental right to confidentiality and privacy, based on principles that have stood for hundreds — literally, thousands — of years, and physicians and other health care personnel have an obligation and a duty to respect that right.

Health care professionals also have an obligation to provide assurances that personal medical records are accurate, timely, and complete; and that a patient's medical information will be confidential and maintained in a secure system. In light of the growing use of technology to maintain medical information, and the growing demands

by multiple parties to access that information, medical confidentiality is now everyone's responsibility. Part of the challenge ahead — to physicians as to the rest of us — is to educate and convey to everyone involved in the health care system that a patient's right to confidentiality is no longer the sole responsibility of the physician.

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