OFFICE OF TECHNOLOGY ASSESSMENT ▪ U.S. CONGRESS

REPORT *brief*

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Health care information reveals some of the most intimate aspects of an individual's life

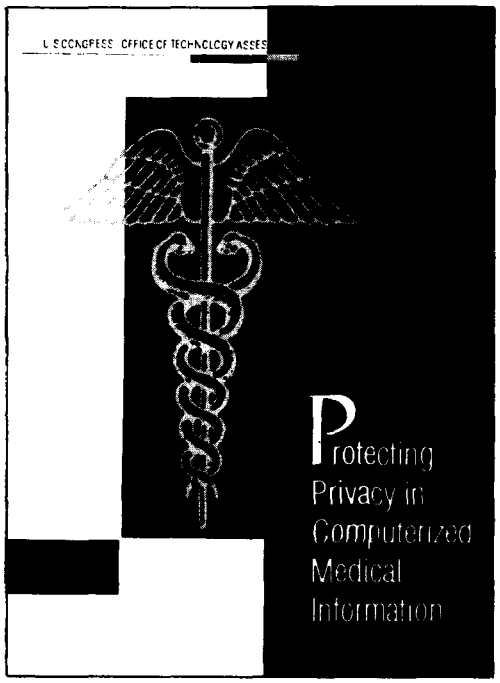
The Clinton administration's health care reform proposal places substantial reliance on telecommunications and information technology to reduce costs and iimprove health care delivery. By linking computerized health information through a national network, the system envisioned in the proposal would allow an efficient exchange of information. This capability could potentially improve patient care and expand resources for medical research and education, while lowering health care costs. While automation may or may not achieve these goals, it will raise serious concerns about individual privacy and proper use of the health care information system.

Protecting Privacy in Computerized Medical Information analyzes the implications of computerized medical information and the challenges it brings to individual privacy. OTA found that the present system of protection for health care information offers a patchwork of codes, State laws of varying scope, and Federal laws applicable only to limited kinds of information. The present legal scheme does not provide consistent, comprehensive protection for privacy in health care information, and it is inadequate to guide the health care industry with respect to obligations to protect the privacy of medical information in a computerized environment. The legal system fails to confront the reality that, in a computerized system, information will regularly cross State lines, and will therefore be subject to inconsistent legal standards.

WHY IS PRIVACY IN MEDICAL INFORMATION IMPORTANT?

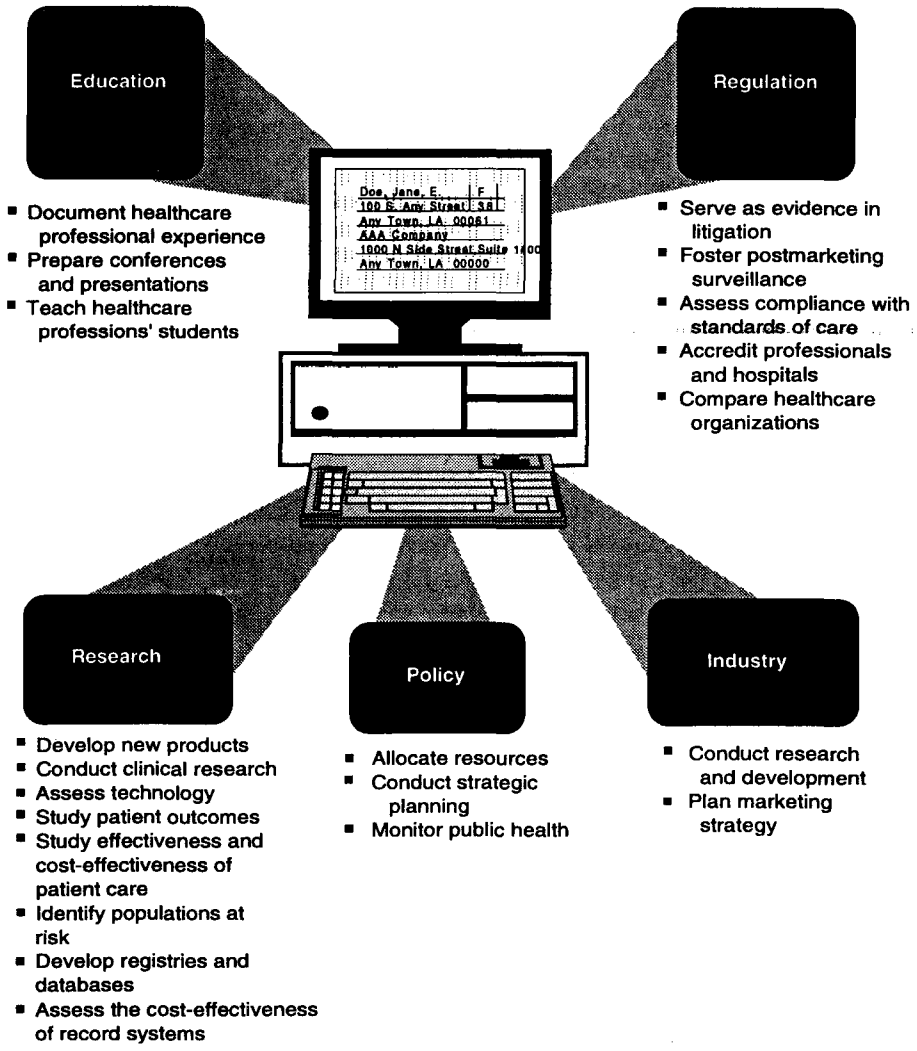
Health information and the medical record reveal some of the most intimate aspects of an individual's life. In addition to diagnostic and testing information, the medical record includes the details of a person's family history, genetic testing, history of diseases and treatments, history of drug use, sexual orientation and practices, and testing for sexually transmitted diseases. Subjective remarks about a patient's demeanor, character, and mental state are sometimes a part of the record.

The medical record is also the primary source for much of the health care information sought by parties outside the direct health



care delivery relationship. These data are important because health care information can influence decisions about an individual's access to credit, admission to educational institutions, and his or her ability to secure employment and obtain insurance. Inaccuracies in the information, or its improper

Secondary uses of patient records



- Document healthcare professional experience
- Prepare conferences and presentations
- Teach healthcare professions' students

- Serve as evidence in litigation
- Foster postmarketing surveillance
- Assess compliance with standards of care
- Accredit professionals and hospitals
- Compare healthcare organizations

- Develop new products
- Conduct clinical research
- Assess technology
- Study patient outcomes
- Study effectiveness and cost-effectiveness of patient care
- Identify populations at risk
- Develop registries and databases
- Assess the cost-effectiveness of record systems

- Allocate resources
- Conduct strategic planning
- Monitor public health

- Conduct research and development
- Plan marketing strategy

The Office of Technology Assessment is an analytical arm of the U.S. Congress. OTA's basic function is to help legislators anticipate and plan for the positive and negative effects of technological changes.

disclosure, can deny an individual access to these basic necessities of life, and can threaten an individual's personal and financial well-being.

At the same time, accurate and comprehensive health care information is critical to the quality of health care delivery, and to the physician-patient relationship. Many believe that the efficacy of the health care relationship depends on the patient understanding that the information recorded by a physician will not be disclosed. Without these assurances, many patients might refuse to provide physicians with certain types of information needed to render appropriate care.

THE COMPUTERIZATION OF MEDICAL RECORDS

The health care industry is currently moving toward linking institutions through a proposed information infrastructure and communications networks. Linkages would

allow transfer of patient data from one care facility to another to coordinate services, and would allow collation of clinical records of each patient over time among providers and at various health sites to provide a longitudinal record, one that forms a cradle-to-grave view of a patient's health care history. Electronically connecting the health care industry by an integrated system of electronic communication networks would allow any entity within the health care system to exchange information and process transactions with any other entity in the industry.

As a result of the linkage of computers, patient information will no longer be maintained, accessed, or even necessarily originate with a single institution, but will instead travel among a myriad of facilities.

Smart cards have also been proposed as a means to computerize and maintain health care information. Smart cards can function to store information, which can be accessed when a patient presents the card to a health care practitioner, and/or as an access control device, carrying out security functions to maintain a more secure and efficient access control system for health care information computer systems.

A major focus of security and confidentiality measures for these systems is preventing privacy invasion by trusted insiders. For online computer systems, security is generally provided by use of user identification names and passwords, and by menus to control access to computer system functions. Some systems also use audit trails to record significant events on a system. However, technology alone cannot completely secure a system. Organizational education, policies, and disciplinary actions supplement technical protection for confidentiality. Smart cards can serve as an access control device, providing the security functions that are normally carried out by the user.

ISSUES IN COMPUTERIZATION OF HEALTH CARE INFORMATION

All health care information systems, whether paper or computer, present confidentiality and privacy problems. Computerization can reduce some concerns about privacy in patient data and worsen others, but it also raises new problems. Computerization increases the quantity and availability of data and enhances the ability to link the data, raising concerns about new demands for information beyond those for which it was originally collected. The potential for abuse of privacy by trusted insiders to a system is of particular concern.

In addition, special policy problems are raised by computerization. Proposed use of a unique patient identifier assigned at birth and retained throughout a patient's lifetime raises concerns among privacy advocates, who claim that if the Social Security number is used for this purpose, linkage of a wide variety of information resulting in dossier type files on individuals would be possible. Policies governing requirements for informed consent could be challenged as well, since currently patients have limited access to their health care record and may have little choice in consenting to its disclosure for certain purposes.

CONGRESSIONAL OPTIONS

Health professional organizations, privacy advocates, and academics specializing in health information privacy believe that as

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computerization of patients' records goes forward, Federal legislation is necessary to address issues of patient confidentiality and privacy. Congress may wish to enact a comprehensive health care information privacy law. Such a law could:

- define the subject matter of the legislation, "health care information," broadly, including the range of information generated, collected, and maintained about individual patients;
- provide criminal and civil sanctions for improper possession, brokering, disclosure, or sale of health care information with penalties sufficient to deter perpetrators;
- establish rules for patient education about information practices as applied to health care information, including access to information, amendment, correction and deletion of information, and creation of databases;
- establish requirements for informed consent by patients to disclosure of health care information;
- structure the law to track the flow of health care information, incorporating the ability of computer security systems to alert supervisors to leaks and improper access to information so that the law can be applied to the information at the point of abuse, not simply to one "home" institution; and
- establish protocols for access to health care information by secondary users, and determine their rights and responsibilities in the information they access.

Congress may also wish to establish a special committee or commission to oversee the protection of health care data; to provide ongoing review of privacy issues arising in the area of health care information; to keep abreast of developments in technology, security measures, and information flow and to advise Congress about privacy matters in the area of health care information.

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