

Medical Records Privacy Violated, Government-Backed Study Finds

Panel Asserts Americans' Loss of Control of Data Is at the Heart of the Problem

NYTimes

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Special to The New York Times

WASHINGTON, Jan. 12—Americans have lost control of the enormous flow of personal medical and health information about themselves, a major Government-sponsored report said today.

Personal data from medical records, the report said, are being used increasingly for nonmedical purposes with little regard for guarantees of privacy or individual rights.

The loss of control is at the heart of the privacy issue, said Dr. Alan F. Westin of Columbia University, author of the report. He is a nationally known expert on issues of privacy.

The report, based on a two-year study, was focused on health records because such records exist on virtually all Americans.

"Every one of us, from the moment of birth certificate to the moment of the death certificate, is a part of the medical record-keeping activity," Dr. Westin said at a news conference arranged by the report's sponsor, the National Bureau of Standards.

Focused on Computer Records

The report focused on computer-organized record keeping, but it said that the abuses that came to light arose from records maintained manually.

Dr. Ruth M. Davis, director of the bureau's Institute for Computer Sciences and Technology, said that the greatly augmented record-keeping ability that computers allow had simply made existing problems a good deal more conspicuous and irritating.

The report said that observance of strict confidentiality of medical records has been seriously weakened by the needs of medical insurance data-keeping and other modern data trends, including the growing use of health information in making social decisions.

Doctors and other providers of primary health care are under many legal and social obligations to disclose personal medical data about individual patients, the report said.

"These obligations are growing greater and greater as society tries to cope with problems of improving public health, occupational health and safety, research into diseases, evaluation of health care systems and similar activities," the report said.

Problems may arise, it concluded, when data identifying individual patients are released to concerns or government agencies without the knowledge of the person involved and sometimes without adequate checks on the validity of the data.

The report cited a case in which a diag-

nosis of mental illness was withheld from a woman under treatment but was relayed to the concern for which she worked. The result was that she learned the diagnosis of her own condition from fellow employees, which had serious ill-effects on her condition, according to the report.

Stigmatizing information such as illegitimacy may be put on a hospital birth record by a hospital employee who simply may not believe the mother when she says she is married, the report said. Conversely, the report added, illegitimacy may be omitted from a birth record if the hospital staff is too busy to check.

Can Determine Hiring

The report said that the flow of medical information "has enormous impact on people's lives." The study said, "It affects decisions on whether they are hired or fired, whether they can secure business licenses and life insurance; whether they are permitted to drive cars, whether they are placed under police surveillance or labeled as security risks, or even whether they can get nominated for or elected to political office."

Dr. Westin said that neither Federal, state nor local laws, at present, contain sufficient safeguards of individual rights and privacy related to medical records.

However, he maintained, as did the report, that the needs of modern medical record keeping and dissemination are not necessarily destructive of individual rights provided the concern keeping the records is conscientious in doing so. The report cited the Martin Luther King Jr. Health Center in the Bronx as an outstanding example of a medical institution that preserves the rights and privacy of its patients in spite of pressures for the data.

The report, titled Computers, Health Records and Citizen Rights, listed about a dozen major conclusions that Dr. Westin summarized in five cardinal points. These were as follows:

¶ Health data systems should be created, altered and periodically altered through public rather than closed procedures.

¶ Every health data system should put limits on relevance and social propriety on the personal information it collects and records.

¶ Every health data system should have clear rules and procedures to insure citizen rights.

¶ Health data system managers should take special measures to protect the accuracy and the security of the data they keep.