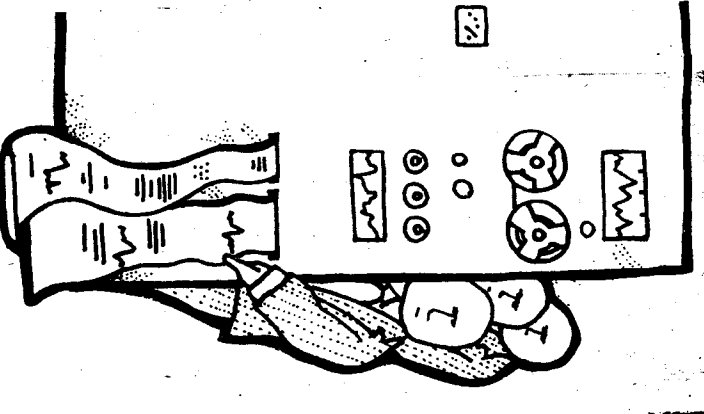


# Sharing Our Health Secrets By Computer



## HEALTH, From Page C1

The family doctor knew his patients, often long and well. He filed facts about their health in the safe crannies of his mind or on 3x5 cards—from birth through childhood ailments and accidents to chronic disease and terminal illness.

Now there are more, and more different kinds of us — patients and practitioners alike. We move more, travel more and take advantage of the training and skills of more specialists. Our doctors and their numerous students must record and file our health histories so they can communicate with each other, and treat successfully.

Our doctors must know. The problem is that others must know, too—sometimes those responsible for contagious disease control must know when an epidemic of measles or mumps breaks out. Criminal justice officials must be able to check a mental patient's history. Carriers must assure their carriers that airport pilots or bus operating cabins to prevent abuse and polluting premium costs. Medical researchers gain survival nature's secrets only by studying individual histories. (A recent example: the connection between sibbested treatment of pregnant women and clear cell vagi-

sters of other social benefit programs—perhaps even to those of the Internal Revenue Service. No overall, enforceable confidentiality rules or guidelines control the system—who feeds what information, who has access to that information and for what purpose. Out health secrets are instantly retrievable in this country and in others, for the rest of our lives and beyond. Tap into the system in Oregon, find out about the heartest, the cancer, the psychological disease and fantasies of the patient in the District of Columbia.

**ODDLY ENOUGH,** the event that caused the medical establishment finally to face up to the speaker had nothing to do with computers which, after all, work according to human demand and reflect a man-made culture. It was the snooty who broke into psychiatrist Dr. Lewis Fielding's California office looking for Daniel Ellsberg's records who shook the elders from their lethargy. The Nixon political operations testifying before the Senate Watergate Committee finished the job. They did not seem to realize they had done anything wrong. "You mean to say, Mr. Ellsberg, that you don't know psychiatrists are physicians?" asked Sen. Sam Ervin, evging the witness stonily under the television

The job of defining the health record is hard enough when you are dealing with files kept by doctors or hospitals for independent adults voluntarily seeking treatment. It is still harder when you consider records for children or dependent people of all ages kept by schools, colleges, prisons or military organizations. For such institutions, voluntary and involuntary, health care is of only secondary interest.

Some have suggested dual record keeping as a possible solution: the same doctor, the same patient, but different sets of records for different uses. This mind-boggling and perhaps impractical suggestion takes various forms, but all involve some sort of divorce between material which is confidential and that which is not — one antiseptic enough to be abstracted for third-party payers, researchers, judicial bodies and all the rest, the other for the doctor and his colleagues.

**POP-OUT!** Critics say so, arguing that, especially in pediatrics, they need adequate, abstractable records to justify diagnosis and treatment. If the revealing little ways in which people deal with each other go into some sort of secondary "eyes only" record, doctors and hospitals may be left out on a limb. (A mental hospital which needs records officially to record why a patient was permitted to go out for the day, for instance,

er's illness with reports on her stay at several well-known mental hospitals and clinics here and abroad. Who could have imagined that a person's intimate dreams and feelings, blurted out in moments of extreme stress to reputable doctors at outstanding institutions as part of one-to-one therapy, would be revealed to a researcher by these same doctors and institutions some 40 years later?

The balance between sharing health records for the public good and limiting access for the sake of personal privacy.

Who can see health records? For what purpose? How much of a health record should be shown to an outsider and how much kept confidential? The professionals in medical recording are the first to say they need some sort of across-the-board restrictions to help answer such questions.

All too often, they report, just put on a white coat and you have it made. There is a general looseness about many hospital and clinic record rooms, which results in file drawers left open or file folders scattered on empty desks during lunch breaks. Security experts counter that they can design "hardware" and "software" to make any personalized data system 95 per cent secure. They can, they say, limit such a system to a small group of people whose access is authorized only after careful examination of

try, some doctors do not answer insurance company requests for patient information fully and promptly, and many who do are very careful as to what facts they supply and in what terms they admit them. (An Illinois psychiatrist even admitted distorting diagnosis for insurance purposes.)

The reasons for such medical evasiveness show up clearly in the Lipson survey. More than three-quarters of the nearly 800 psychiatrists surveyed fear a breach of confidentiality. In responding to insurance companies, half are certain the companies do not preserve confidentiality. Although they feel, ironically, that patients under psychiatric care are sometimes better risks than those who are not, almost all the respondents also tend to feel that psychiatric information in the wrong hands might prejudice these same patients' jobs.

Such fears are compounded in the complex legal area, where psychiatrists must often make difficult decisions about the disclosure of confidences—with and without patient consent. The American Psychiatric Association has officially stated that its members have the "right to dissent within the framework of the law," and Dr. Maurice Grossman, the APA's expert on third party confidentiality matters, has advised them not to be intimidated by legal subpoenas

used in Sweden, where a psychiatrist treating a patient is not called upon to evaluate or testify in court about the case. Instead another professional carries out these tasks.

**THE NEWEST ASPECT** of the "informed consent" question involves the concept of permitting a patient to see his own health record so he can check its accuracy and correct errors. (This principle is now embodied in the 1974 Privacy Act and the Buckley amendment on school records, though the latter has caused considerable difficulties for teachers and administrators.) Many doctors fear the impact, but patients are unaware of the issue, but might be able to grow wiser. Should a patient be able to see his record? Should he be in a mental hospital or a surgical bed, whether or not a doctor judges him incompetent or simply unready to deal with the full details of an illness?

Such questions create polarization. At one end of the spectrum, a civil libertarian contends that "informed consent" would be meaningless if the patient did not have the right to see his record and that any doctor who attempts to deny that right should be compelled to obtain a court order compelling that a psychiatric hospital's records cannot be treated to judge his patient's competence to deal with their records, he will go out of business.

Between the two poles are many who would limit the patient's right to see his record in some way. They would defer to the doctor's judgment in certain cases—when, for example, a patient is suffering from terminal cancer and cannot accept the truth. Or they would refer a doctor-patient disagreement to a second physician of the patient's own choosing or to some other "independent" judge.

Baffling problems remain. How can society strictly limit access to health records and, at the same time, prevent the patient's access to his records? How can patients be assured that "identifying" data from records, thereby ensuring both privacy and the future research value of the medical information—and then reinserted so patients and their lawyers can review and challenge the record? Will both patient and doctor become so involved with the "informed consent" question that medical record-keeping changes for the worse—fit for patients' eyes perhaps but so blind as to be of little value to medical professionals?

Sometimes sparty triumphs over the right to know. One mental hospital has refused patients the right to see their records, though they have the right to sue for their records. But it is clear that whatever individual patients may do, our computerized society hungers for personal information and that the varied demands for medical records will continue to grow. The issue can be met only by the development of clear rules balancing the needs of patient, practitioner, research, commerce and society itself. The task is complex, even infuriating, but not impossible of solution.

files which record the identity of inquirers, coding sensitive material including vulnerable psychiatric material, even requiring finger or voice prints to get into secure areas. But such things are very expensive.

It is a matter of matching the security to the need. Someone is going to have to make some hard value judgments as to what is needed—and if the medical professions and other such groups do not make them, the government will probably step in to do it for them.

Congress has already shown its concern with records confidentiality. The recent review legislation mandates the development of coding procedures which will "provide maximum confidentiality as to patient identity." And it has teeth: a \$1,000 fine and/or six months' imprisonment for inappropriate disclosure of information. The Department of Health, Education and Welfare's strong draft confidentiality policy regulations, to be published soon, could have a ripple effect. It is significant that each of the major national treatment of post review, possibly includes some form of post review.

**THE MOST ENTICING** solutions proposed for health confidentiality problems center around the doctrine of "informed consent." This doctrine, once they play the patient's consent to a medical procedure, has come to mean also his consent to starting that medical information to be kept on file. And this has led to the doctrine that the doctor has a duty to assure its accuracy and protect himself against mislabeling and misdiagnosis.

Think back on the last time you signed a health insurance claim form. Unless you are an extraordinary consumer—a veritable Ralph Nader—your consent was anything but "informed." It was probably given in a routine matter; you did not consider the possible consequences of words like these (most often in tiny type in an unobtrusive place on the page): "I hereby authorize the undersigned physician to release any information acquired in the course of my examination or treatment; such information shall be available to all persons, including insurance carriers, health, pharmaceutical, re-payment organizations, employers, unions and insurance companies. You are authorized to permit information X or its representatives to obtain a copy of your records pertaining to the examination, treatment, history, prescriptions and benefit payments."

Many argue that the breadth of the "blanket" consent form in common use today makes it hard for doctors and institutions to deny information to third party payors—but not the patient given them permission to tell all. Narrowing the definition that patients can consent to is the direction of needed reform. So is coding in such a way that sensitive diagnoses and conditions especially sensitive diagnoses and conditions can be coded in a way that would refer to "Number 7," for example, instead of to the lurid symptoms of a psychiatric illness.

Benjamin Lipson, an executive with a Boston life insurance company, reports the results of a survey which confirm a general suspicion: in the vulnerable field of psychiatric

might wish it had done so when he is killed in an auto accident and the hospital is sued for damages.) And outsiders may find a way to get confidential notes anyway.

What's more, in a time when more and more medical personnel are involved in treatment, more communication is needed, not less. The words "seen by psychiatrist," "examined by psychiatrist," or "seen by psychiatrist" are no longer sufficient. Psychiatrists must keep complex instructions, whole team of people, and a variety of specialists must be able to get into all sorts of files.

The balance between destroying health records or expunging them for the sake of personal privacy and keeping them for research contributing to science and to his- tory.

What should stay in the health record? Should information be allowed to percolate, unchallenged, over the years? If it is not re-examined periodically, or its archaic nature brought to the attention of file users, warn the civil libertarians, there are human dangers. They cite cases like that of a schoolboy, sick with measles, who is later hospitalized, where he is given the measles virus. He later dies of the disease.

A number of worried physicians and patients would be ready to experiment with a new formula. Dead records would be kept for children—the doctor's working notes, containing hunches and unconfirmed diagnoses, and a permanent record belonging to the child-consumer and kept by him. The working record would be reviewed each time the patient saw the doctor; ultimately such pieces of information would be either expunged or inserted into the permanent record. Since the permanent record is subject to review, it is almost any other, it would be sealed for a period after graduation, and then destroyed.

**ON THE OTHER** side of this particular confidentiality issue are the medical historians, the epidemiologists, the geneticists and the anthropologists. They are all interested in meaningful facts and all interested in the past.

As a result, Dr. Marx says, epidemiological research and genetic studies are difficult or impossible to carry out and we know practically nothing about the past incidence of mental illness. He urges that wherever possible we save records, while preserving confidentiality to the maximum. He suggests that the medical profession should be able to access records of people who are dead, but that the records should be sealed for a period after graduation, and then destroyed.

king signs. Evidently not. Stung by such a cavalier attitude, and fearful of the extent to which it might reflect a general erosion in physician-patient confidentiality, the American Psychiatric Association, representing some 23,000 practicing psychiatrists, began a series of meetings with a wide range of other medical, legal and consumer groups. These continued last fall in Cambridge, Mass. The same had happened at the Key Brainerd. The meetings were held in the American Medical Association and American College of Surgeons and the American Civil Liberties Union.

The Key Brainerd conference did not attempt fully to answer the complex questions raised at its meetings. Rather, it sessions outlined the magnitude of the problems and the chief areas of concern and voted to establish a commission to address them in depth.

Please call for the commission to get under way this year. Some may feel it's job will be an easy one: just carry requests for information, out medical facts indiscriminately to non-medical consumers.

**BUT EXQUIRITELY** delicate balances must be struck between the patient's right to privacy and the society's need to know. These include:

- The balance between the minimum required to keep meaningful records and the maximum needed to protect confidentiality.
- How to define the health record? How to ascertain what should stay in it and what should be expunged or inserted into the permanent record? In view of the risks involved, should it be possible to have a permanent record to society's memory or retained only in a limited way?

It stands to reason you do not have to worry about what does not go into the record in the first place. Obviously, some information is needed to write an adequate medical record. Equally obviously, other information— anecdotal gossip, for example— is not.

In between lies a gray area— information which might or might not be needed for the sake of the patient's health, now or in the future. Take children's records. Doctors are usually trained to track children with "dear" the years, concerning "childhood" and "adolescence" usually generate extensive records full of sensitive judgments and biographical—social, environmental and biological. Such data about the health of a 2-year-old could stay in his record 70 years!

Does all of it need to be there? Doubtless, some children's advocates hold that children's medical records—especially those of the deprived children who frequent courts and social welfare agencies—are often abused. Parole officers, welfare and other officials can frequently get hold of them at the spin of a telephone dial; they travel, and use them alone to identify all in the name of "the best interests of the child."

**TWO POWERFUL** trends, one technological and one social, have made it easy for health records—once secure in the privacy of the doctor's office or hospital room—and available only to medical personnel—to be abstracted again and again and forwarded, often with our "consent," to the visible and unknown inquirers.

One is the great surge in computer technology, and with it, the increased feeding of personal health information into machines, which can handle many millions of pieces, with a second and more vast quantities of material.

There are, as Harvard Prof. Arthur R. Miller has noted, the contents of the individual's medical record to appear more and more in the public domain. The data file bespeaks reliability, as does the myth of computer infallibility. And the centralization of information from widely divergent sources creates serious risks of using facts out of context. Whose business is it, after all, that a patient once consulted an internist about impotence or a heart condition?

The other main trend which tends to increase access to our health records is the growth of "data" party. In the privacy of American covered by health insurance, more and more people are asking questions about it—and processing the answers. Americans visit the doctor 13 million times a year and complete at least 20 million hospital days. Most of us do not contemplate, indeed do not know, that those receiving the records of visits to doctor and hospital may feed them, write them up, and enter them into the computer, and all into the memories of their computers and, through network arrangements, into those of a growing number of data centers throughout the country.

The Medical Information Bureau (MIB) for instance, a computerized center, feeds data set up by the commercial companies to the Medical Information System (MIS), containing complete mental health histories, links psychiatric hospitals, clinics and outpatient health centers in the New England area.

In the public sector, Medicare, Medicaid and other public health programmers already are keeping millions of health records. Now the new PEROs (Peer Standards Review Organizations) will add their demands to those of government insurers and justifiers. They will need vast amounts of personal information to prove that health care services rendered by the Medicare, Medicaid and other payors are of high quality.

A disconcerting specter has turned up to haunt us, nine years short of 1984: We are all hooked up to the Big Computer. Facts about your heart condition, my ulcer, the neighboring child's mental retardation, recorded when we visit doctors and clinics or stay in the hospital, are transferred automatically in to the data system of a national health insurance program tied to the com-

