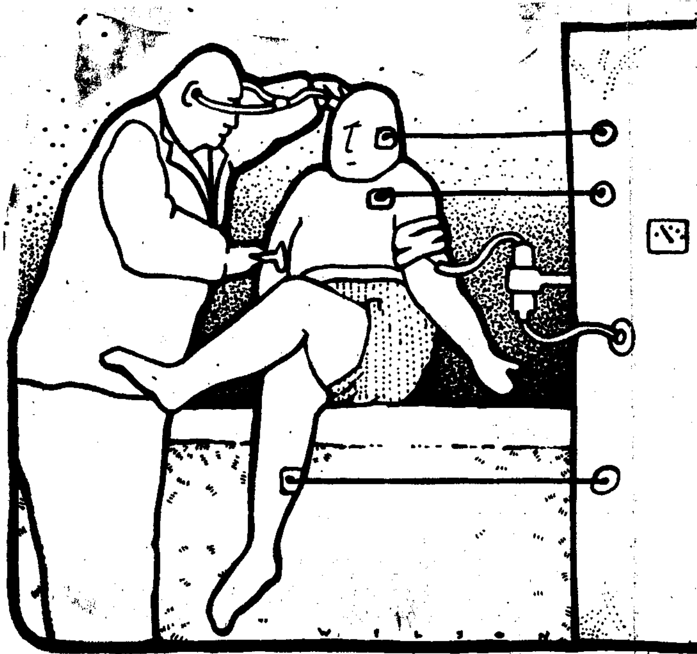
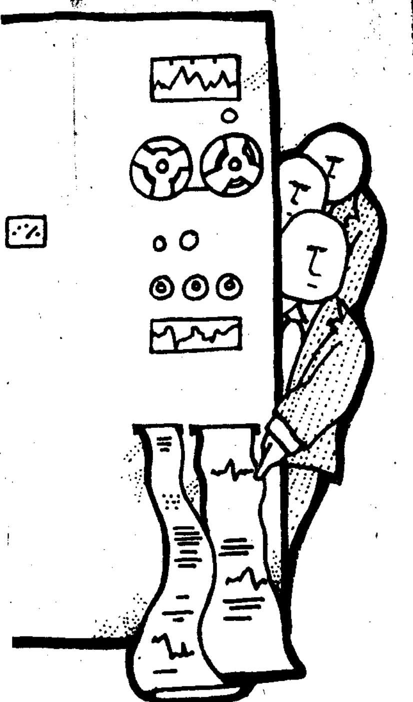


Sharing Our Health Secrets By Computer



HEALTH, From Page C1

The family doctor knew his patients, often long and well. He filed facts about their health in the safe crevices of his mind or on 3x5 cards—from birth through childhood sickness 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 assistants 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 smallpox or measles breaks out. Criminal justice officials must be able to check a mental patient's history. Carriers must assure their customers that aircraft pilots or bus operators are in top condition. Insurers must verify claims to prevent abuse and spiraling premium costs. Medical researchers can unravel nature's secrets only by studying individual histories. (A recent example: two-generation research which established the connection between stilbesterol treatment of pregnant women and clear cell vagi-

puters 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 purposes. 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 heartbeat, the cancer, the psychological dreams and fantasies of the patient in the District of Columbia.

That is the specter.

ODDLY ENOUGH, the event that caused the medical establishment finally to face up to the specter had nothing to do with computers which, after all, work according to human demand and reflect a man-made culture. It was the snoops 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 operatives 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. Ehrlichman, that you don't know psychiatrists are physicians?" asked Sen. Sam Ervin, eyeing the witness sternly 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 interests.

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.

COP-OUT? Critics say so, arguing that, especially in psychiatry, 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 neglects 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 regulations to help answer such questions.

All too often, they report, just put on a white coat and you have it made. There is a genial 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 supply 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 900 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.

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 records room and available only to medical personnel—to be abstracted again and again and forwarded, often with our "consent," to the invisible 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 instructions a second and store vast quantities of material.

There are, as Harvard Prof. Arthur R. Miller has noted, dangers here: As information accumulates, the contents of the individual dossier tend to appear more and more impressive despite the dubious accuracy of the data. The fat 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 "third party" involvement in health matters. With the majority of Americans covered to some extent by health—or at least by hospital—insurance, more and more people not responsible for our health care are asking questions about it—and processing the answers. Americans visit the doctor 1.2 billion times a year and complete at least 38 million hospital stays. Most of us do not contemplate, indeed do not know, that those receiving the records of visits to doctor and hospital may feed them, warts 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 for medical data set up by the insurance industry, is available to hundreds of commercial companies. The Multistate 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 PSROs (Peer Standards Review Organizations) will add their demands to those of government insurers and cost justifiers. They will need vast amounts of personal information to profile practitioners and in other ways to see to it that medical services rendered by the Medicare, Medicaid and maternal and child health programs are necessary and of high quality.

A discomforting 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-

klieg lights.

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 22,000 practicing psychiatrists, began a series of meetings with a wide range of other medical, legal and consumer groups. These culminated last fall in a Confidentiality Conference held, ironically, at Key Biscayne, Fla. Some 50 organizations sent representatives. They ranged from the American Medical Association and American College of Surgeons to the National Congress of Parents and Teachers, the Mental Health Law Project and the American Civil Liberties Union.

The Key Biscayne conference did not attempt fully to answer the complex questions raised at its meetings. Rather, its sessions outlined the magnitude of the problems and the chief areas of concern and voted to es- [illegible] a commission to address them in depth.

Plans call for the commission to get under way this year. Some may feel its job will be an easy one: just curb requests for health information, tell doctors and hospitals to stop giving out medical facts indiscriminately to non-medical snoops.

BUT EXQUISITELY 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 go in, what should remain, what should stay out? How to determine to what extent the scrivener's hand should be stayed, in view of the risks involved, so that some information at least is lost 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 a child's health over the years, collecting "longitudinal data" with an eye to preventing future illnesses. This practice usually generates extensive records full of tentative judgments and guesswork—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? Doubting it, 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, unprotected, from agency to agency and many see them along the way, all in the name of "the best interests of the child."

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 psychotherapist, July 11," or "acute cholecystitis-cholecystectomy 1974" no longer suffice when a whole team of professionals and paraprofessionals must follow complex instructions. Dual record keeping might result in all sorts of foul-ups.

• 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 history.

What should stay in the health record? Should information be allowed to petrify, unchallenged, over the years? If it is not reexamined 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 an infection, who fainted in class and was treated in the infirmary. Returning later, he glimpsed the note "Epilepsy?" in his medical file. Too terrified to discuss the matter, he carried with him for years the notion that he is an epileptic.

A number of worried physicians and parents would be ready to experiment with a new formula. Dual 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 each piece of information would be either expunged or inserted into the permanent record. School health records, subject to more squirreling than almost any others, would be sealed for a period after graduation, and then destroyed.

ON THE OTHER side of this particular confidentiality seesaw sit the medical historians, their eyes on a future when facts not now considered meaningful may become all-important. Boston University Medical School's Dr. Otto Marx, an historian and court psychiatrist, argues that too many records have already been lost.

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 in tight compartments, to enable medicine to move into the next technological era without the loss of vital material.

Most people, Dr. Marx adds, have little concern about the publicity they may spark after their deaths. But — tip the seesaw back again— their families may be disturbed.

Scottie Fitzgerald Smith, the only child of novelist F. Scott Fitzgerald and his wife Zelda, was so upset by the psychiatric material in a biography of her mother that she could not finish reading the "Zelda" manuscript. The book documented her late moth-

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 health records confidentiality. The peer 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 Health Insurance proposals includes some form of peer review.

THE MOST INTRIGUING solutions proposed for health confidentiality problems center around the doctrine of "informed consent." This doctrine, once simply the patient's consent to a medical procedure, has come to mean also his consent to sharing that medical information with others. And this has come to include his right to see his own record 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." Or, worse still, "To all physicians, hospitals, clinics, dispensaries, sanitariums, pharmacists, prepayment organizations, employers, unions and insurance companies: You are authorized to permit insurance company 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—has not the patient given them permission to tell all? Narrowing the form so that patients can consent only to the disclosure of certain pertinent parts of their records is a needed reform. So is coding to mask especially sensitive diagnoses and conditions. Insurors and doctors could then 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 psychia-

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 for other fields in federal legislation such as 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 principle, most patients are unaware of the issue, but the idea is gaining ground. Should such a right be absolute or qualified? Should any patient be able to see his record, whether he is 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 supporting that decision. At the other, a psychiatrist who runs a private hospital says that, if he cannot be trusted to judge his patients' 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, firmly establish the patient's right to review them? How can names and other "identifiers" be stripped 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 bland as to be of little value to medical professionals?

Sometimes apathy triumphs over the right to know. One mental hospital recently offered patients the chance to see their records—and very few took advantage of the opportunity.

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.