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Patients' privacy and the confidentiality of medical records are in the news. Proposed State consumer protection legislation has been criticised as permitting officials to invade the confidences of doctors' files. Federal Police and Health Department officers have been chastised in the news media for the way in which they have conducted certain investigations of alleged fraud and other offences on the part of doctors. A recent issue of the Bulletin[1] criticised the seizure of patient medical files carried out in 'the recent wave of heavy-handed raids on doctors' surgeries'. Proposals for compulsory reporting of suspected cases of child abuse and proposals to extend compulsory reporting to cases of cancer promote heated debates and generate strong passions.

In March and April 1981 at least three medical conferences in Sydney examined the implications of computerisation of health records for confidentiality. The Royal Australian College of General Practitioners' Third National Conference on Computers in Medical Practices examined the topic in the context of the utility of computerised medical records for accounting, educational, diagnostic and treatment purposes. The General Practitioners' Society in Australia, Fourteenth Annual Conference, examined the topic against a background of practitioner anxiety concerning certain recent investigations of doctors and their patients by federal agencies. The Inaugural Congress of the International Organisation of Private and Independent Doctors looked at the issue in the context of the 'preservation of private practice' in a world increasingly demanding detailed public accountability for the expenditure of the health care dollar.

Until now, the legal protections for private information in Australia have been few and uncertain. The Federal Attorney-General has asked the Australian Law Reform Commission to report on new laws for the protection of privacy in federal areas of concern. In 1980 the Commission published two discussion papers, with tentative proposals for new laws.[2] During November and December 1980 public hearings and seminars were conducted in all parts of Australia to receive comments and criticisms on the discussion papers from expert and laymen alike. Many submissions were received from all branches of the medical and health care professions. These are now being analysed. A final report with proposals for draft federal legislation may be expected towards the end of 1981.

DATA PROTECTION LAWS AND MEDICAL RECORDS

Some of the acutest problems of medical privacy result from the new information technology, as health care records are increasingly computerised and become accessible in remote terminals by means of telecommunication linkages. In Western Europe, where data protection laws have been developed over the past decade in response to the rapid computerisation of personal information, a common feature of the legal protections for the individual has been the provision of an enforceable right of access to personal data about oneself. The very simplicity of this notion is seen as potentially the most effective means by which, in an age of data bases, the individual can maintain control over his information profile, on the basis of which increasing numbers of decisions will be made affecting his life. Applied to the field of medical and health care records, special problems arise. These were the subject of many submissions to the Law Reform Commission. They are clearly relevant to the future design of Australia's privacy laws.

Some of the recurring questions raised in the public hearings may be listed:

- Should patients generally have a right of access to medical and health care records about themselves? If not, what exceptions should be provided, according to what principle and with what alternative safeguards for accuracy and up-to-dateness of personal medical records as these are increasingly centralised and computerised?

- Should a parent have a right of access to medical information about a child and if so, to what age and with what exceptions if the child claims a privilege to have advice on an intimate personal medical problem kept confidential with the doctor?

- Should courts have an unlimited right of access to personal medical files, as is the case in all jurisdictions of Australia except Victoria, Tasmania and the Northern Territory? Or should there be a general privilege against disclosure of medical confidences to a court, unless the patient consents? Should a court be required to weigh the competing interests of the administration of justice on the most relevant data against the claim of doctor and patient to the privacy and confidentiality of their relationship before requiring the production of medical records under subpoena?

- Are psychiatric records, with their specially intimate disclosures, in a special class, requiring different regulations both in respect of patient or parent access, on the one hand, and non-consensual court access on the other?

SCIENTIFIC RESEARCH AND CONFIDENTIALITY

One matter which has not attracted very much attention in Australia and scarcely raised a mention during the Law Reform Commission's inquiry is the resolution of the competing claims of individual privacy and of scientific research. In September 1980 the Council of Europe held a conference on this aspect of European law at Liège in Belgium. The report of this conference and the papers delivered there have only recently reached us in Australia. It was pointed out that nowhere in Europe, where data protection laws have been enacted, has research, including medical research, been regarded as a 'protection-free area'.[4] Before computerisation of health care records the relatively few and rather vague criticisms about research access to medical files were generally answered by equally vague reference to professional codes of ethics. But as European data protection (privacy) laws were put into force, and personal data was seen as an extension of the personality of the subject entitled to enforceable legal protection and redress, greater sensitivity was raised concerning the use of personal medical data even for a subject so important as medical research. Nor has the concern been limited to Europe. The American Psychiatric Association and other American associations were among the first to amend their professional regulations to comply with demands for better data protection and privacy for the subjects used in research studies. In August 1977 a conference held at Bellagio adopted principles which incoporated emphasis upon voluntary agreement of the subject to the collection of his data for research purposes. The principles emphasised informed consent as the leading precondition to the use of such data. Priority was to be given, as far as possible, to the use of anonymised data. The right of access to one's own data — the golden rule of privacy law — was to be observed, wherever a subject might be identified.[5]

When it reported in 1977 the United States Privacy Protection Study Commission gave particular attention to privacy in scientific research for three stated reasons:

- There is a growing demand for information collected and maintained by administrative agencies. As the demand increases, the dissemination of personal data tends to increase and therefore requires additional protection.
- The number and variety of research activities proceeding of any given time raise serious doubts about the ability of the research community to enforce adequate measures by the old techniques of self-regulation.
- Dangers could arise from the use of individually identifiable research and statistical records for administrative, regulatory and even law enforcement purposes. Where there is a file, there is usually an administrator with reasons why he should have access to that file.[6]

There is no doubt that the use of medical records in research has produced great benefits for mankind. For example the side effects in the use of oral contraceptives were discovered primarily as a result of large-scale studies in which hospital medical records were used. These studies would have been virtually impossible to carry out had the actual consent of the numerous patients been required. Commenting on these issues Gordis and Gold have asserted:

> Society has a vital stake in epidemiologic and other medical research. We must ensure that the dignity and privacy of subjects will be protected without hindering the advancement of knowledge and disease. The social contract that facilitates the existence of individuals within social groups requires that each individual occasionally yields some of his rights, including privacy and freedom of action, for the benefit of society as a whole.[7]

At the moment the rules which balance the rights of the data subject and which protect him against misuse of data about him or alert him to any possible harm he may suffer, exist less in the law than in the realm of fair practice and decent conduct, to be judged by standards of the individual researcher. Australian law has little to say on the topic. The potential coming together of many sources of personal information as a result of the new information technology and the spectre of the total personal data profile will probably require better protection in the future than we have needed in the past. As the Council of Europe conference indicates, this is not just a local concern of a few people sensitive to individual privacy.

It is an international debate which is largely the product of new technology and its realised potential. We will hear more of this debate in Australia. It is important that the medical profession, as it embraces the computer's enormous potential for good, is alert also to its limitations and possible dangers.

FOOTNOTES

1. The Bulletin, 7 March 1981, p.25.

2. Australian Law Reform Commission, Discussion Paper No. 13, Privacy and Intrusions, 1980; ibid, Discussion Paper No. 14, Privacy and Personal Information, 1980.

3. Evidence Act 1958 (Vic), s.28; Evidence Act 1910 (Tas), s.96; Evidence Act 1980 (NT), s.12.

4. S. Simitis, 'Data Protection and Research: A Case Study on the Impact of a Control System', in Papers for the Tenth Council of Europe Colloquy on European Law, 23 September 1980, Scientific Research and the Law, mimeo. See also J. Visser, 'Control Mechanisms and Bodies with Special Reference to Medical and Genetic Research', in Papers, and P. Sieghart, 'Need for Control Systems and Interests Involved', ibid, and L.F. Bravo, 'International Aspects of the Control of Scientific Research', in ibid.

5. Simitis, 5.

6. United States Privacy Study Protection Commission, Personal Privacy in an Information Society, 1977, 567.

7. L. Gordis and E. Gold, 'Privacy, Confidentiality and the Use of Medical Records in Research', Science, 207 (4427): 153, 206 (11 January 1980).