THE SOUTH BRISBANE HOSPITALS BOARD

PRINCESS ALEXANDRA HOSPITAL JUBILEE WEEK 1981

BRISBANE, FRIDAY 24 JULY 1981

RIGHTS OF PATIENTS : CONFIDENTIALITY AND PRIVACY

The Hon. Mr. Justice M.D. Kirby Chairman of the Australian Law Reform Commission

July 1981

THE SOUTH BRISBANE HOSPITALS BOARD

PRINCESS ALEXANDRA HOSPITAL JUBILEE WEEK 1981

2.2.

ents Anto

BRISBANE, FRIDAY 24 JULY 1981

RIGHTS OF PATIENTS : CONFIDENTIALITY AND PRIVACY *

The Hon. Mr. Justice M.D. Kirby Chairman of the Australian Law Reform Commission

THE AUSTRALIAN LAW REFORM COMMISSION AND PATIENTS' RIGHTS

The Australian Law Reform Commission has become concerned in the subject of patients' rights, confidentiality and privacy because of a number of tasks given to it by the Federal Attorney-General for the reform of laws which are a Federal responsibility in Australia. Basically, medical law in this country is a State responsibility. It is not, as such, one of the areas of the law assigned by the Constitution to the Commonwealth Parliament. Nonetheless, in a number of areas the Commonwealth has a legitimate concern. In the Territories, for example, the Commission was asked to prepare a report on Human Tissue Transplants. That report has now been adopted in the Capital Territory and the Northern Territory. It is also the basis of new legislation in Queensland. I gather it will soon be adopted in Victoria and that it is under active consideration in New South Wales. Thus a proposal framed for a Commonwealth Territory has become the basis of State laws on a complex, sensitive and controversial medical topic.

Three current projects before the Australian Law Reform Commission require us to look, directly or indirectly, at the law governing medical and hospital records. These projects are:

<u>Privacy.</u> Our inquiry into Federal laws for the protection of privacy in Australia. Certainly in the Territories and possibly, in due course, in respect of data bases linked by telecommunications, Commonwealth laws are needed for the better protection of individual privacy. The need has arisen in part because of the development of new intrusive technology, such as computer and surveillance devices. In part, the greater powers of government officials to intrude into our lives represent a danger to privacy that must be checked with appropriate new, effective safeguards. This is not a local concern only. It is an international concern of all developed Western communities.

- Evidence. A second project we have is our inquiry into the law of evidence. This may seem, at first blush, to be remote from the issues of medical confidentiality and patients' rights. However, it is the law of evidence which governs the compellability and admissibility of evidence in courts and tribunals. In about half of the jurisdictions of the United States evidence law prevents questions being asked concerning treatment of a patient, without that patient's consent. In Australia a similar inhibition exists only in Victoria, the Northern Territory and Tasmania and then limited to civil trials and with some notable exceptions. The reasoning behind the protection of medical confidences by the law of evidence in these jurisdictions, is founded in the belief that upholding public health and the ability of people, without inhibition, to consult doctors and hospitals, is even more important, as a social good, than securing all relevant evidence in courts of law and tribunals.
- Child Welfare. The Law Reform Commission has also been asked to report on the law of child welfare in the Australian Capital Territory. Here again is a Territorial inquiry which may have value to State colleagues. The issue of child abuse and society's response to it raises questions of medical confidentiality. The Queensland Minister for Health, Mr. Austin, was recently reported as saying that the 81 cases of child abuse reported in Queensland in the last six months were merely the 'tip of the iceberg'.1 He described child abuse as a growing problem in Queensland and said some parents 'shopped around' for treatment for their children by visiting various hospitals and doctors to disguise the fact that the victims had suffered previous injuries. He foreshadowed more powers for police and doctors to ensure that maltreated or neglected children were taken into care by the State. Similar problems confront the Law Reform Commission in the Capital Territory. But the resistance of the medical profession to duties of compulsorily reporting suspected cases of child abuse are well known. Doctors and hospitals are resistant to becoming, as they say, agents of the State for compulsory reporting. They fear a diminution in their effectiveness. One medical practitioner told our public hearing in Canberra that he would never report a person who came to him for treatment, or treatment of his child, whatever the law said. Respect for the patient's confidentiality is generally well entrenched in the medical profession of our country.

New problems have occurred or come to light in recent months affecting the celivery and organisation of health services in Australia, health record-keeping practices and the privacy of patients' records. These developments suggest the need for new rules that will bring completeness and clarity to the law governing confidentiality of patients' records, including in the hospital context. Among the problems to which I would draw specific attention are three:

- 3 -

The growing use of automated data processes in both private and public sectors of health care and related services.

Changes in the delivery and organisation of medical health care services affecting privacy and confidentiality of patients.

Intrusions by police, Health Department and other government officials in response to suspected cases of abuse of medical funding by doctors and other members of the health care professions.

I will deal with these problems, each of which affects patients' rights, in turn.

COMPUTERISATION OF MEDICAL AND HOSPITAL RECORDS

The use of computers in both private and public sectors of health care and rélated services is already widespread and is growing at a rapid rate. Computers are now in use in the health field in all Australian States and the Australian Capital Territory. In Victoria, for example, many hospitals have either installed their own system or utilised the services of local computer service bureaux. In New South Wales, a number of systems have been developed and introduced into hospitals on a regional basis. Similar developments have occurred in other States. Some Adelaide hospitals, for example, use personnel and payroll computer services provided by the Health Computing Service at Monash University. Other local computer service bureaux operate in Victoria. In the future, if they do not already exist, we can expect computer linkage systems between höspitals in Australia, between Australian hospitals and computer service bureaux, and between Australian hospitals and service bureaux and those overseas. The Health Computing Service on a fee for services basis, provides services for approximately 130 separate clients, some being annexes of specialist departments, within a larger health care complex. The centre provides services specifically related to medical records in excess of 40 clients. The main utilisation of these computer facilities by hospitals relates to admission and discharge information, patient location, condition and accounts, and morbidity statistics. In hospitals, the computer centre facility is utilised through installing an on-line system, being a terminal, printers, and associated software.

Each of these hospital systems is connected to the computer centre by a 'dedicated' Telecom landline, that is, a telephone line only utilised by the hospital involved. Ten hospitals in Melbourne are currently² linked to the computer centre in this manner. The hospitals are not, however, linked to each other, or to other institutions or computer centres. It appeared in 1979 that interest was growing among health care providers in a linkage of that type and that some form of inter-hospital linkage was likely to be introduced in Victoria within the next decade. Such an inter-hospital linkage system is now operating in New Zealand (known as the Central Patient Medical Index (PMI) introduced in 1976 and operated by the New Zealand Health Department).³

CHANGES IN HEALTH CARE SERVICES

Changes in the delivery and organisation of medical health care services place privacy and confidentiality at risk to a greater extent than could ever have been envisaged in the period when the framework of rules for determining the legal implications of the doctor-patient relationship were developing. The existence of patient. medical records is a relatively recent event in the history of delivery of medical care. For centuries, doctors enjoyed a very direct and personal relationship with their patients, which rarely involved a third party, much less a hospital computer services bureau. The original concept of the doctor writing notes for his own benefit, around which the contractual and equitable rules establishing duties of secrecy were established, has inevitably changed to one where he and many others write notes for the benefit of colleagues and other health care providers who are, or might become involved, in the care of the patient concerned.⁴ Other related developments include that of the 'Problem Oriented Medical Record which makes all information more readily available, enhancing the possibility of illegal intrusion.⁵ Rather than encouraging patient confidentiality on important issues, the POMR probably detracts from it. Another new development in the hospital context is that of 'peer review', the implementation of which is being promoted by the Australian Council on Hospital Standards. Peer review is a formal process requiring the gathering of statistical information and descriptive reporting on the performance of individual clinicians. The purpose of this process is to allow feed back to aberrant professionals. The peer review system provides access to information by the professionals concerned; and any clinician whose work is questioned has the right to appeal in respect of any of his or her privileges which might be curtailed. Other developments occurring generally in the medical field⁶ are:

shorter working hours for doctors, more partnerships and more locum services;
increased mobility amongst doctors and patients, resulting in transient professional relationships and communications;

better educated and increasingly independent patients willing to seek second medical opinions and to change doctors;

- 5 -

the growing surplus of doctors;

the shift towards salaried medical employment;

the development of teams consisting of general practitioners, specialists, nurses, social workers, psychologists, physiotherapists, to be found in a diversity of settings such as community health teams, health centres, abortion clinics and sports medicine clinics;

developments in clinical education of medical and other health students in a wide variety of innovative community settings;

from hospital to hospital. Thus, some hospitals leave the medical record at the foot of the patient's bed or allow him to take the record home;

. a growing circle of secretarial, clerical, administrative and computer staff concerned with the flood of patient information.

These are but some of the new phenomena in the medical field. When taken together, they provide an environment where patient privacy and confidentiality are at risk.

Existing legal remedies for mishandled information address themselves to the relatively rare situation where the subject becomes aware of the mishandling as a consequence of being hurt by it. He may then obtain damages to compensate him for what he has lost as a consequence of the mishandling, or he may obtain an injunction to prevent repetition. But compensation for loss after the wrong is done is an unsatisfactory way of securing fair record-keeping practices in hospitals. An analogy can be drawn between hospital record-keeping practices and factory safety precautions. The factory worker who loses an arm as a consequence of the factory owner's negligence may of course sue for damages. But this common law remedy is not considered sufficient by Parliament as an inducement to the maintenance by factory owners generally of adequate safety precautions. Detailed regulations set out safety precautions to be followed in factories for the protection of workers; and an inspectorate is assigned the task of ensuring that these safety standards are complied with. The law does not limit the weapons in its armoury to those which apply after a particular worker is injured. 127

The problem of ensuring compliance with adequate data security practices in hospitals is compounded by the fact that, as a consequence of the introduction of electronic data processing, there is an increased chance of people being hurt without their knowing of it. Medical records are already of great interest to health insurers, government payers, law enforcement authorities, welfare cepartments, schools, researchers, credit grantors, and employers. Attempts are made in the hospital context to avoid the curiosity of such groups being satisfied at the expense of patients' privacy. But pressures and opportunities for disclosure are great. There is certainly no effective law to prevent widespread disclosures, and a lack of generally adopted data security standards makes intrusion into the hospital record a real possibility. At present in Australian hospitals, information sharing in the hospital context itself it not limited on a 'need to know' basis, but may be communicated merely to the idly curious, a situation of which patients are generally unaware. A patient whose blood group has been misrecorded or transferred inaccurately from a data storage facility elsewhere, may very soon discover that his personal information has been mishandled. But a parent whose child has been incorrectly assessed in a hospital may not be aware that this is the reason why a welfare benefit, such as the handicapped child's allowance, has been disallowed or cancelled. Varying ethical codes apply. Indeed, in certain areas of health care practice there is a total absence of any kind of ethical code. Varying levels of appreciation of the legal rights and liabilities arising from a particular situation, due, quite understandably, to the vagueness and the vagaries of the existing legal framework, exist. As a result, disclosure and other information handling practices will vary from place to place, ranging from the dangerously restrictive - a computer program concerning the patient's general treatment denies a pharmacist information which would have indicated that an incorrect drug had been prescribed - or dangerously slack - where a nursing aide reveals details of a patient's health and financial position to a private investigator.

- 6 -

OFFICIAL SEARCHES

One of the most unhappy features of medical practice in recent years in Australia has been the growing number and, let us be frank, the growing necessity of official inspection of medical and other health care records produced by the rash of the so-called 'Medibank fraud' cases. The issue is very much a live one today. In Sydney on 16 September the Institute of Criminology of Sydney University is to conduct a seminar on the subject of medical professional crime. Almost every week, fresh evidence comes before the courts of frauds against the Commonwealth revenue or other offences provided for by Commonwealth law. In such circumstances, some diminution of doctor/patient confidentiality, in the investigation of such crimes, would seem to be

able. Even in the case of legal practitioners' privilege, so well entrenched and long bished, the privilege may be overridden in certain circumstances where the dealing രങ് enlawyer and client is itself fraudulent or criminal. It would appear to me to be too Dela facile to say that a doctor's records should not be examined without his consent (or even his patient's consent) when investigating an offence alleged against the doctor or patient of the set the criminal law and breaches of statute to the consent of the very person under suspicion on other persons upon whom he may sometimes exercise influence. The Pharmaceutical efit Scheme of the Commonwealth currently involves payments of substantial sums by the Commonwealth, presently running at in excess of \$300million per year. Unhappily, es of Diain fraud or practices forbidden by the National Health Act do occur, involving medical practitioners and their patients. Committees of inquiry have been established as an alternative to court actions against doctors, but whether in court or in a committee of inquiry, provision is made for sanctions. Sometimes, let us be perfectly frank, sanctions are wentirely warranted. I have been impressed with the sincerity with which presentatives of the various branches of the medical profession have asserted that their re concern is not to protect the dishonest, fraudulent doctor or patient, but to ensure that in investigating cases, the privacy of patient records should, so far as possible, be guarded and secured, and the investigation limited so far as possible so that it does not unnecessarily upset sensitive, worried and sometimes highly vulnerable patients.

One matter which has caused anxiety is the analysis of prescribing patterns followed by particular medical practitioners. It is claimed that this intrudes upon the privacy of the relationship between doctor and patient. On the other hand, the Department of Health has put to us the contention that reports on doctors' prescribing practices are generated by computers sometimes at the request of the individual doctor and frequently for general statistical information on the use of particular drugs. The machinery, it is said, provides an opportunity for doctors to compare their own particular prescribing patterns with the average of other doctors. It is acknowledged that in some cases there are justifiable reasons for differences. But in other cases, it is claimed, there is a legitimate social entitlement to call differences to attention and even, possibly, to raise the question of irregularity. Mention was made in one submission to us of the use of Depo-Medrol. The average dispensed price of pharmaceutical benefits for this drug is less than \$5 for five ampoules. The drug has a Commonwealth dispensed price of \$14.07. It is the highest priced of the relevant long-acting injections. Long-term usage of the drug is said to produce unwanted systemic effects, including so-called 'moon-face' changes.

-7-

The Australian Drug Evaluation Committee has reported on adverse drug reactions. It is claimed that, in these circumstances, there is a legitimate social interest in prescription patterns, which go beyond the normal in relation to this drug. It is expensive to society as a whole. It may be potentially damaging to patients. At the very least doctors who are well out of line with the average should, so it is said, be counselled, lest they are not aware of problems and side effects.

In days gone by, before national health and computer analysis, it is true that the prescription patterns of doctors were not considered a legitimate matter of concern to Departments of Health, Commonwealth or State. The introduction of public funding and the potential of computer scrutiny has certainly diminished the absolute confidentiality of the relationship between the health care provider and the patient. I realise that some medical practitioners and others, both in private practice and in hospitals, have their doubts about this procedure. On the other hand, there will certainly be many in our society who will say that he who pays the medical piper may call the tune, at least to the extent of protecting the revenue against clear exceptional claims and protecting patients against individual practitioner ignorance or oversight. Certainly, recent cases in the context both of the files of solicitors and of doctors suggest that the scope of the power of government officials to examine confidential client and patient records is greater than it was hitherto assumed.⁷

TOWARDS EFFECTIVE PRIVACY LEGISLATION

The Law Reform Commission has proposed comprehensive laws in the Federal sphere for the better protection of individual privacy, including in relation to medical confidences. Time does not permit a detailed discussion of our proposals. Four of these recommendations made are particularly important in the present context. They relate to:

- . Subject access to his personal, medical or hospital record.
- . Limitations on disclosures from the record without the subject's authorisation.
- . Formulation, through the medium of a Privacy Council, of legally enforceable standards for data security in record-keeping practices.
- A new uniform regime of control over the entry, search and seizure powers of all Commonwealth and Territory officials, so that normally these powers should be exercisable only on the basis of a warrant granted by a judicial officer on reasonable grounds of suspicion relating to specific matters, the warrant stated in detailed and particular terms.

- 8 -

propose to deal only with the first three of these subjects.

PATIENT ACCESS TO HOSPITAL RECORDS

One can approach the issue of patient access to his hospital record in two ways. of all, one can say that, as a matter of ethics and morality, people's information practices should be fair and that fairness can only be achieved where there is 'mutuality', orea sharing of knowledge and control, between record-keeper and record-subject. Access is essential to achieve mutuality; and mutuality in record-keeping practices is essential if individual autonomy is to be upheld in the face of developments in information practices which may put the value at risk. If this argument does not appeal, then resort may be had to a more pragmatic approach, namely, that because there is now a risk of medical records being widely shared with others interested in their contents, it is crucial that the record be kept as accurate as possible and for the patient to know what is being recorded and to correct inaccuracies that may affect education, career advancement, or overnment benefits. The possibility of access will create greater objectivity and couracy in recording information about patients; and, of course, in the no doubt limited number of situations in which any right of access would be exercised by patients, there will besa double-check, involving the patient himself, of the accuracy of the material recorded therein. Thirdly, an argument related to the foregoing in support of access runs as follows: those who might oppose access would nevertheless agree that there ought to be limitations on disclosure of the hospital record. Most opponents to access would nevertheless agree that a hospital record ought generally not to be disclosed without the consent of the patient. But a patient cannot really give consent unless he knows to what the is consenting to and he will not know what he is consenting unless he has access to the record from which it is proposed to make disclosure.

-9-

Submissions to the Commission on the issue of access fall into three groups. At one end of the scale are the various associations and organisations representing doctors which, by and large, quite vigorously oppose access. At the other end of the scale are the representations from individual doctors and allied health professionals who take the view which can rather crudely be summed up in the submission of one to the effect that 'the patient might just as well have access to his record. Everybody else does'. Sitting on the fence are some groups representing medical record administrators, who, while generally in agreement with the principle of patient access, are acutely aware of the attendant problems. The essential issue is whether, even if there is a genuine value in creating mutuality in the hospital-patient and doctor-patient relationship, a right of access to written records would be of much help to the average patient. Would it in fact prove counterproductive to his interests, bringing about double-entry hospital record-keeping, causing the patient who gained access to become confused or anxious as a result of his newly acquired information, and so antagonising doctors as to encourage corrosive attitudes of non-cooperation: attitudes capable of spill-over into other areas of work.

10 -

As noted above, the Commission has received submissions opposing access from doctors representing the interests of large institutions, and from associations, formal and informal, representing the interests of doctors themselves. These submissions, although varied in nature and content, basically provide variations upon the one theme, namely, that the doctor should decide what patients need to know about their records, and that any interference with the doctor's judgment might lead patients to become worried, undermining good medical care. The submissions emphasise the fiduciary relationship between doctor and patient, pointing out that access would be a violation of the duty to withhold information which would be harmful to the best interests of the patient as a matter of sound medical judgment; or summing it up, 'doctor knows best'. The submissions claim that patient access could itself increase the danger of unauthorised access, particularly if a copy is released to the patient; and they emphasise the threat which patient access would hold to the developing process of 'peer review'.

None of these fears has been borne out by the United States experience, where access is already fairly widespread, and by the experience of record-keepers in the health care area in Australia which presently allow access.

First, as to the United States experience, the Committee on Government Operations, to which was referred the Bill for a Federal Privacy of Medical Information Act, to protect the privacy of medical information, in its report of March 19, 1980⁸, indicated that it found near universal acceptance of the basic concept of patient access to medical information. Those who testified in favour of some type of patient access included the American Medical Association, the American Hospital Association, the American Medical Records Association, the American Psychiatric Association, the National Commission on Confidentiality of Health Records, the American Academy of Pediatrics, the American Civil Liberties Union and the Health Research Group.

्राष्ट्रक इ.स.स्ट

Secondly, as to the experience of health and welfare organisations which presently allow subject access, I refer to the example of a child welfare charity, studied by the Law Reform Commission, which keeps files on each child received into its care, including the reports received from the referring organisation, medical reports, psychiatric reports if applicable, and a contract worked out with the natural parent, or guardian, at the time of admission. All of these files are written in such a way that when the child reaches 18 years of age, that child should be able to read it. In preparing the file on a child, subjective assessments and value judgments are avoided as much as possible. The social worker knows that it might be read! Assertions such as that a child's mother has the morals of a prostitute' or that his father 'seems a violent man', found in other health care records studied by the Commission, are avoided by this organisation. The objective facts are set down in this agency's files, rather than the professional's subjective conclusions drawn from those facts. Files are maintained on prospective foster parents, who also have the right of access. Once again, these files are delicate and highly personal, containing social histories and behavioural assessments obtained from separate interviews with each prospective parent and from an interview with both applicants conducted together. The experience of this organisation with such forms of access has been highly positive.

Obviously in Australia, with so much professional resentment, access could only be gradually introduced in the hospital context. The Law Reform Commission's proposals include one for a Privacy Council, which could establish standards for record-keeping practices for hospitals, including limited access rights. Not only should access rights be introduced gradually in the hospital context, they should also initially be limited to that part of the record which might be considered the 'official record', consisting of all personal factual data about the patient — social and family histories; complaints; tests; examination results; records of diagnoses; treatment summaries; drug regimens; payment information; and any other data which might be described as 'official'; and access should be subject to certain limitations — as where the interests of the subject himself, of a third party or of the public, would be detrimentally affected.⁹ Introduction of access rights to hospital records, if pursued in this way, should pose no problems and prove of benefit in securing privacy protection in the Australian hospital context.

0.7

LIMITATIONS ON DISCLOSURE

The rules for disclosure provided by the law of contract and by equitable doctrines concerned with confidential information provide an inadequate framework for controlling disclosure in the hospital context. The Commission's proposals, if adopted, would substitute a statutory code for vague judicial precedent. The essential elements for that code would be as follows:

- . The dissemination of information from the patient's record should not exceed that necessary to satisfy the purpose for which the information was collected. This is a flexible concept which recognises that complex administrative settings produce a high incidence of flows of information dictated by practical necessity. Medical records administrators, couriers, nurses, cardiologists and surgeons may all be required to handle a medical record in the course of hospital treatment of the data subject. This is an instance of multiple handling of a record dictated by administrative necessity.
- Disclosures from hospital records made in response to inquiries from areas of Federal government such as Social Security, or from health insurers, the purpose of the inquiry being to corroborate or verify financial or other information <u>supplied by the patient</u>, should be permissible, but only where the patient has been given notice of the practice of the hospital in supplying information for a routine 'double-check', and where he has been given an opportunity of suggesting acceptable alternative means of verification if the one accepted by the hospital is unsatisfactory to him. In the hospital context, the concept of 'necessary use' would encompass access to the records by those on the hospital staff who 'need to know' details concerning the patient's condition and treatment, but not otherwise. The 'routine check' concept would apply only where the patient is notified of a routine practice, to which the hospital is party, of providing verification of details supplied to a third party by the patient himself.
- Disclosures which are not reasonably necessary for the purpose or purposes for which the information was acquired should not be made from the patient's hospital record unless -
 - .. with his authorisation, or in the case of an incapable person, the authorisation of someone legally empowered to act on his behalf;
 - .. under authority or compulsion of law;

- 12 -

where the disclosure is made in good faith on reasonable grounds and is likely to realieve a serious threat to the life or health of another individual or to the life for health of the subject himself;

in case of police inquiry concerned with an emergency in connection with the prevention or investigation of the commission of a serious offence involving adapter to individuals or public safety;

to the relevant authorities, where there is an imminent threat to public health or safety arising from circumstances unrelated to any breach of the law, requiring the authorities to trace possible carriers of a disease or to take preventative measures on a large scale to avoid a serious threat to public health or safety.

Restant

Disclosures from the hospital record for audit purposes, or disclosures for statistical research purposes, which, subject to appropriate controls, should be permissible. But examples of the following kind must be avoided:

A woman had been treated for a sensitive condition by a medical practitioner who was still a student in his chosen field of specialisation. Her case was written up as a case study as a requirement for this course. Investigation revealed that the woman was identified both by description and by name in that study.¹⁰

CONTROL OVER STORAGE

fan de states en

Through the mechanism of the Privacy Council¹¹, standards should be developed to apply generally throughout the extended care facility and care hospital system, requiring reasonable measures to be taken by record-keepers to prevent improper access or accidental release of information. In relation to the destruction of information, the hospital record-keeper should not keep personal patient information once it is no longer relevant for the purposes which govern the collection of the information or to any continuing relationship between the record-keeper and the subject, a proposition elaborated upon below.

Data Security in Hospitals. A Privacy Council, which could include amongst its members representatives from hospitals associations and other such organisations, could elaborate standards reflecting a basic principle that data should be as secure as possible to preserve patient confidentiality consistent with the computer being used to its full advantage to facilitate the delivery and administration of high quality patient care. In this context, the experience of The London Hospital in developing a data security program for its computer, is instructive. The experience documented in 'Some Problems of Confidentiality in Medical Computing'¹² shows how flexibly a computer may be used to limit access on a 'need to know' basis and to reduce the possibility of unlawful intrusion. The writers of this article make the point¹³ that:

As medicine becomes more complex, both in concept and technology, more and more people must inevitably be involved in the care of an individual patient. It is doubtful whether this is fully realised by the general public. If it was, they could in theory decide what degree of dissemination of information about themselves they would find acceptable, having appreciated the degradation of quality of care that must result from limitations on dissemination. From a practical point of view such a decision could be very difficult and the situation currently seems to be one in which the public by implication trust the health care profession to proceed in a reasonable fashion. It follows from the increasing number of people involved in health care that it is impossible to maintain perfect confidentiality of information on any system, manual or computer. Thus The London Hospital has 4,000 employees and it would be possible for some individual, for instance, to don a white coat and stethoscope and pose as a doctor, thereby gaining access to a patient's record folders; ward staff are encouraged to challenge unrecognised persons but this cannot be a total safeguard against a determined person.

Two comments may be made on that assessment. First, written in 1976, it precedes the growing mood of consumers of all forms of services and products to have a greater say in matters relating to their quality and mode of delivery.¹⁴ A Privacy Council, which would represent industry, consumer and government groupings in society, would provide a satisfactory compromise between the two extremes of limiting decision-making on matters affecting the consumer entirely to persons gaining from the delivery of the service and of seeking full public discussion and endorsement of every decision affecting the consumer. Secondly, where hospitals make decisions concerning their own data security in isolation from the experience of other hospitals and from the experience of computer users generally, there is a risk that they may fail to keep abreast of developments in the area, for example, new standards for encryption of personal information, which are both economically feasible, practically possible, and highly desirable in the interests of patient confidentiality. Again, a Privacy Council would provide a mechanism for keeping hospitals abreast, and encouraging the sharing of knowledge, of developments in modes of achieving desirable data security standards.

- 14 -

Retention of Medical Records. In a paper delivered in 1979 to the Eighth Australian Conference on Medical Records¹⁵, Mr V.F. Kiessling recommends against the destruction of medical records. Mr Kiessling takes this view, because, if a patient were to suffer an injury because no records were kept or because they were faulty or deficient; he would be entitled to sue the hospital in negligence: there is always the possibility that records of patients, if retained, might assist in preventing harm befalling them on a re-admission. Mr Kiessling also alludes to the fact that a cause of action for negligence does not arise until such time as the damage to a patient manifests itself. and in the case, for example, of exposure to excessive radiation, this could be many years after his discharge from hospital. So also, in the case of children, there are special rules relating to the commencement of the period of limitation in which an action might be brought. A well kept hospital record may assist the hospital in defending itself. He concludes that 'the responsibility to keep full and accurate medical records and to keep them accessible is not only necessary for patient care but also a way of ensuring that if a dispute arises between a patient and a third party or the patient and the hospital those records can be used in evidence. Don't forget that well kept records can be a hospital's best defence.'16 •

Obviously, the issue of destruction of records generally, but in particular, of health records, with the epidemiological, historical, genealogical and other advantages to be obtained from their retention, is a difficult one. It is clearly not practicable to frame detailed standards of general application to govern the issue of destruction. As with the framing of security measures, this is a matter best left to discussion, advice and where necessary to regulatory control, devised by the proposed Australian Privacy Council.

CONCLUSIONS

Public debate on the Commission's proposals for laws to protect the privacy of Australians has displayed broadly based community support for information privacy rights. Surveys conducted for the Commission indicate that an overwhelming majority of Australians believe that they should have a right of access to records held by record-keepers such as employers and credit bureaux. Hospitals will not be immune from the tide which runs in favour of greater rights for the patient. At present there are no general and effective individual rights in hospitals and other record-keeping areas, upheld by the law. The time is near when action will be expected.

- 15 -

FOOTNOTES

This paper draws extensively upon a paper by Associate Professor Robert Hayes, Law Reform Commissioner, 'Privacy and Confidentiality in Hospitals', delivered to the Victorian Hospitals Association 1980 Annual Conference, 27 November 1980, Melbourne, <u>mimeo</u>. Professor Hayes is the Commissioner in charge of the Australian Law Reform Commission inquiry into privacy laws.

1. The Australian, 13 July 1981, 2.

See Australian Law Reform Commission, 'Privacy : Medical Records', Research Paper No. 7, April 1979.

3. ibid.

2.

4.

G.H. Dreher, 'Privacy and Medical Records — The Effect on Patient Care', Paper delivered at the Eighth Australian Conference on Medical Records, October 1979, <u>mimeo</u>.

 R.S. Ryback, The Problem Oriented Record in Psychiatry and Mental Health Care', Grune & Stratton Inc., United States, 1974.

 P. Bates, 'Legal and Ethical Aspects of Medical Confidentiality and Privacy in Australia', University of New South Wales, School of Health Administration, Working Paper No. 78/3.

 Crowley & Ors. v. Murphy, Full Court, Federal Court of Australia (FC 43 of 1979), 19 March 1981, mimeo. Cf. Grant v. Downs (1977) 11 ALR 577.

 United States, 96th Congress, Second Session, House of Representatives, Report 96/832, Pt. 1, 33-40.

 See Australian Law Reform Commission, <u>Privacy and Personal Information</u>, (ALRC DP 14), June 1980, Chapter 4, especially 52ff.

10. Privacy Committee of New South Wales, Five Years 1975-1980, 105..

11. ALRC DP 14.

12. Barber & Ors, (1976) 2 Journal of Medical Ethics, 71-3.

- 16 -

The New South Wales Department of Consumer Affairs, in its 1980 Annual Report tabled in Parliament 11 November 1980, reports a marked increase in consumer complaints, including complaints against doctors. Sydney Morning Herald, 12 November 1980, 3.

Melbourne, 11 October 1979, 'Legal Aspects of the Retention of Medical Records'.

ibid.

Ĵ.

id., 72.

laa

10.

- 17 -