LX MA MATHESON, I.D. Freedom of information: patient access to medical records.

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FREEDOM OF INFORMATION

Patient Access to Medical Records

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INTRODUCTION

The thesis of this paper is that patients should have a statutory right of direct access to their hospital medical records. In New Zealand, much has been done to protect the privacy interests of patients in regard to their medical records, yet their right of access, which is perhaps equally as important, has never been considered as a legislative possibility. In fact, one recent attempt [1] to introduce freedom of information legislation specifically precluded the right of an individual to gain direct access to his medical record. The fact that in the United States there are a number of statutes, state and federal, which grant such access, is one indication that the New Zealand situation may be an unjustified and restrictive state of affairs.

With this concern in mind, an attempt will be made to deal with the following questions.

I. What is the nature of, and what use is made of medical records?

II. What is the current state of the law and administrative policy in relation to a patient's right of access to his medical record?

III. What are the arguments used in support of current law and administrative policy?

IV. What arguments can be raised in support of a statutory right of access?

V. What has been the response of other countries in providing for such access?

VI. If legislation is to be introduced giving a patient a right of access to his medical record, what form should it take?

1. MEDICAL RECORDS AND THEIR USE

Because medical records vary so much, it is difficult to formulate a general description. Depending on the extent of the patient's atay in hospital and the nature of his illness, the record may contain a mixture of fact, opinion and speculation relevant to the patient's treatment. Such information may relate to identification of the patient, his personal and family history, results of physical and special examinations, prognosis and diagnosis, a diary of any medical and surgical treatment, progress reports, follow-up information and autopsy reports. In fact, anything which hospital staff consider relevant may find its way onto the medical record.

The medical record is used primarily for purposes of treatment, present and future, but the hospital is also concerned with a wide variety of research programmes which may depend to some extent on the information contained in medical records. Epidemiological research, i.e. the study of diseases and their transmission, is one area which relies heavily on medical record information.

Hospital medical records are also used as a basis for supplying information to the Departments of Health and Social Security as well as the Accident Compensation Commission. The police, insurance companies, employers and other third parties with the patient's consent may also rely on medical record information from time to time.

11. CURRENT LAW AND ADMINISTRATIVE POLICY

A. Legislation

There is no statutory provision in New Zealand which gives a patient a right of direct access to his medical record. The only provision which relates to the disclosure of medical records in the hospital situation is section 62 of the Hospitals Act 1957. Section 62 merely provides that no hospital employee shall give any person not employed by the hospital, any information concerning the condition or treatment of the patient, without the patient's consent. There is nothing in section 62 which compels disclosure, even when a third party has been brought in and the patient's consent obtained.

It is worth nothing that in the Accident Compensation system, a claimant does have a right of access to medical reports held by the Commission in certain circumstances, i.e. in relation to hearings of application for review, section 154 (6) of the Accident Compensation Act 1972 provides as follows:

> "The Commission or the Hearing Officer, as the case may be, may receive such other relevant evidence and make such other enquiries as it or he thinks fit, and may for that purpose appoint a medical committee. All evidence and information so received or ascertained (otherwise than at the hearing) shall be disclosed to every party to the review."

The effect of this provision is to confer on the applicant, a right of access to such information. Such information typically consists of medical reports relevant to the claim at

hand. The term "such other relevant evidence" refers to evidence other than that presented by the applicant under section 154 (5) of the Act. Section 154(5) entitles the applicant to present relevant evidence in support of the application for review.

B. Common Law

The common law is particularly relevant in considering such rights of access in New Zealand. This is so because in the absence of applicable legislation, it is the common law which becomes authoritative on questions of access. In New Zealand and the United Kingdom, the courts have not dealt directly with the question of whether a patient has a right of direct access to his medical record. However, a number of cases have dealt with the question of property rights in information and documents held by professionals and which are used in the course of their professional service. Before considering these cases it is perhaps worth noting that in 1977, the Ombudsman had occasion to consider the question of access to medical records. The relevant case [2] involved a complainant who alleged unreasonable refusal by officers of the Wellington Hospital Board to release to her her medical file recording the Wellington Hospital history of certain medical treatment. The complaint was not sustained on the basis that to recognise an automatic right of access would reduce the subjective content of medical records in the future, a development which would be detrimental to patients in the future. The Ombudsman was also of the opinion that present Hospital Board policy of allowing indirect access through a responsible third party was satisfactory.

In the United States and the United Kingdom, the courts have traditionally adopted a similarly negative approach. The case of Leicestershire County Council v. Michael Faraday and Partners Ltd. [3] was not one directly concerned with access to medical records, but involved the question of who had property rights to information prepared by a professional in the performance of a contractual service to a client, a situation analogous to the hospital-patient relationship. The defendant was a company carrying on the business of rating valuers, being employed by the plaintiffs to value hereditements in their area. The agreement under which the valuers were employed contained no express provision requiring documents prepared by the defendants to be handed over to the plaintiffs.

The plaintiffs brought an action for the delivery up of all documents, books, maps and plans prepared by, or in the possession of the defendants for the performance of their duties. It was held that there was no basis in law for the plaintiffs action. Mackinnon L.J. stated:

> "If there is nothing in the contract on which the plaintiffs can rely to establish that they are right in saying that these pieces of paper are their property, by what rule of law otherwise can they assert that that is so? I know of none." (p. 215)

It was intimated that had the relationship been one of principal and agent, the plaintiffs would have succeded. However, since it was a professional - client relationship, different consideration arose. Mackinnon L.J. stated further:

> "I think it would be entirely wrong to extend to such a relation what may be the legal result of the quite different relation of principal and agent. These pieces of paper ... cannot be shown to be in sense the property of the plaintiffs .... They are documents which he has prepared for his own assistance in carrying out his expert work, not documents brought into existence by an agent on behalf of his principal, and, therefore, they cannot be said to be the property of the principal."(p.216)

Goddard L.J. in coming to the same conclusion, relied on the case of London School Board v. Northcroft [4] in which the plaintiffs sought to establish property in certain memoranda held by surveyors whom they had contracted with. The judge in that case was quoted by Goddard L.J. as saying:

> "The paper belonged to Messrs. Northcroft, the ink belonged to Messrs. Northcroft, and the brains that put the calculations on paper belonged to Messrs Northcroft and I want to know how that document which came into existence ever became the property of the plaintiffs. In my judgment it never did." (p.218)

In the United States the courts have taken a more ambivalent view. Gotkin v. Miller [5] a 1974 New York case involved an action brought by the plaintiff to obtain access to any medical records held by various hospitals which might relate to her. The records were required by the plaintiff to verify various factual data included in a book she was writing about her experiences as a voluntary mental patient. The lower New York Court held that neither statutory, administrative nor decisional law of New York recognised a patient's right of access to his medical files. On appeal [6] the decision was upheld. After a review of a number of New York cases it was stated that:

> "All of them indicate that patients have certain rights in their records short of the absolute property right to unrestricted access ...." (p.129)

The rights which patients did have arose primarily from local legislation, in particular the discovery provisions of New York law.

The Courts on other occasions have shown a willingness to recognise a patient's right of access to his medical record. This willingness has given rise to a distinction being drawn between property rights in the physical substances of the record and the less tangible information contained within the record. The case of Wallace v. University Hospital of Cleveland [7] involved a refusal by a hospital to allow a patient access to her medical record for purposes of assessing damages in a negligence action against the hospital. In a seperate action the plaintiff filed a petition for mandatory injunction seeking the production of these records. It was held that although the record was the property of the hospital:

> "... the patient has a property right in the information contained in the record and as such is entitled to a copy of it." (p. 918)

This view was followed in the case of Pyramid Life Insurance Co. v. Masonic Hospital [8] where the plaintiff was pursuing a mandatory injunction for inspection and copying of his medical record. It was held that although the paper and other materials on which the records are maintained are the property of the hospital they are mere custodians of the information contained therein.

It is submitted that there is a lack of consistency in cases dealing with property rights to medical records. On the one

hand there are those which refuse to recognise a property interest sufficient to support a right of access. On the other hand, there are those which have shown a willingness to recognise at least a property right in the information contained within the record. It is submitted that a satisfactory right of access can only be provided for within the context of statutory law, since only legislation can produce the degree of certainty at present lacking in the common law.

C. Administrative Practice

With the lack of relevant statutory provision and binding common law precedent, the question of patient access to medical records has been left in the hands of Hospital Board administration. At present the policy of Hospital Boards throughout New Zealand is to refuse patients direct access to their medical records [9]. However, it must be recognised that although a patient is not personally allowed to see his own medical record, the hospital authorities in most cases do not object to perusal by a responsible agent, usually a third party doctor or solicitor instructed by the patient. Although it is true that Hospital Boards have certain obligations to act in accordance with the principles of informed consent [10] and the guidlines contained in the various patient Bills of Rights [11] which have recently come into existence, there is nothing in either of these reference points which require the hospital to allow direct access.

111. WHY ARE PATIENTS DENIED DIRECT ACCESS TO THEIR MEDICAL RECORDS

It has been suggested that the reluctance of the medical profession to recognise a patient's right of direct access to his medical record has its roots in the historical development of the profession [12]. Ison makes the point that the medical profession devoted much of it's time to serving the lower socio-economic classes, a large proportion of whom were illiterate. Thus, the medical profession developed a habit of communicating orally. The habit became entrenched into what is now seen by the medical profession as a traditional and essential aspect of their method of operation. The reliance on oral communication may also be a result of the close physical relationship between doctor and patient. Because the doctor and patient are usually in close physical proximity with one another, oral communication must have always seemed to be the appropriate means of conveying information.

Another possible explanation of present administrative policy is the fact that in part, the patient's recovery may be a psychological process, i.e. it may depend on the patient's belief that the doctor always knows what he is doing, that medical science is certain, and that a cure is inevitable. It may be that the fallacy of these propositions could only be sustained by maintaining the practice of oral communication between doctor and patient. Written information is more likely to contain the truth and nowhere is this more so than in the case of medical records where it often becomes clear that what may appear to the patient as fact is merely opinion and what may appear as a certainty may be clearly a contentious issue on which different doctors hold different opinions.

Apart from these speculative explanations, a number of reasons have been put forward by the medical profession in support of policy which prohibits patients from seeing their own medical records. The underlying basis of these reasons is that it is not in the patient's best interests to see his own medical record.

First, it is argued that patients cannot interpret medical records and an oral account is sufficient and, indeed, the only way a patient can come to know the content of his medical record.

This argument can be subjected to a number of criticisms. The fact that a person cannot understand information is no reason for denying him direct access to it. It may be a reason why the patient does not want access, or why the patient wants assistance in interpreting complicated parts of a record, but it can never be a reason leading to the conclusion that direct access should be totally denied. In any event, it is likely that most patients who request access to their records will understand most, or, at least part of the record. If they don't there seems no reason why some members of the staff should not give them assistance.

Secondly, it is argued that patients will misinterpret information, thus leading to unnecessary confusion and anxiety on their part.

Again those who may be unclear about something can always seek assistance from the staff. Even if they don't seek assistance, the confusion and anxiety resulting from misinterpretation will probably not equal the anxiety which results from being told that direct access is not permitted.

Thirdly, it is argued that the frank comments which sometimes find their way onto medical records may have a detrimental psychological effect on the patient. For example, it may create hostility towards the hospital staff, and result in non-compliance

with instructions.

Here, one may well ask why the comment is offensive. Is it because it might be an inaccurate comment? Is the description of a patient as "uncooperative" merely the result of a patient being uncharacteristically depressed on the day the opinion was formed? If it was, then the patient should not be denied the opportunity to challenge the opinion. As with the other reasons put forward, it does not support total denial of direct access, although it may be a reason for exceptions to a general right of direct access.

Fourthly, much of what is written on a medical record is opinion and often very frank opinion. It is argued that doctors would be constrained in including such opinion on the record if they knew the patient might ultimately be allowed to read it. This fear seems like such a remote possibility that again it is no justification for total denial of direct access. In fact, one study has found the fear to be largely illfounded [13]. One might also query whether this argument is not in effect, a rejection of the notion that the doctor should be accountable to the patient. Accountability, or at least the prospect of it, is one way in which the standard of care may be effectively maintained or even improved.

Fifthly, it is argued that if a patient were allowed direct access to his medical record, he may annoy the hospital administration by demanding that it be altered in some way. Hayt has stated: [14]

> "It is undesirable to allow a patient or his family to inspect his chart. He or they may find comments by nurses, interns or other members of the professional staff which may be considered uncomplimentary or incorrect. The patient may then attempt to have the record changed, or cause annoyance to the administration or the professional staff."

But surely the "annoyance" is worth it if information is found to be incorrect. In fact, disastrous consequences may flow from proceeding on an assumption that incorrect data is in fact correct. One might also consider how much more annoying will be the patient who is denied access to his medical record. Research results do not provide much support for this fear of patient annoyance [15]. In one study undertaken in a New York federal hospital, only 5% of those requesting access to their medical records had sought an amendment to the record [16].

Sixthly, it is argued, or feared, that the examination of

records by a patient may produce unwarranted litigation. In a recent survey of New York doctors which attempted to identify physician attitudes towards patient access to medical records, 51% feared increased litigation [17].

But surely access to medical records will give a potential litigant a better basis on which to make a decision as to whether to commence litigation. Access to his medical record may, in fact, reveal information which convinces him to discontinue legal action. If there is information on the record which is likely to incriminate the hospital, then they should be accountable rather than be permitted to hide behind a veil of secrecy.

In New Zealand, the fear of a negligence action should be virtually non-existent in view of the Accident Compensation Act 1972, which covers personal injury resulting from medical and surgical misadventure.

Seventhly, and perhaps most effectively it is argued that medical records should not be made directly available to patients since there may be information on the record which could detrimentally affect the patient. For example, what effect will it have on a patient to learn he has a low I.Q., is prone to mental disease, or worse still, is terminally ill? Could it really be justified if access to such information contributed to the deterioration of the patient's condition or possibly a suicide attempt? This issue will be discussed more fully in relation to the question of exceptions to disclosure, but it must be noted that again this arguement does not support total denial of direct access.

IV. ARGUMENTS SUPPORTING DIRECT ACCESS

The arguments in support of direct access can be catagorised under three headings. First, there are arguments which are based on democratic principles. Second, there are arguments which are based on the practical benefits to be gained from access to medical records and thirdly, there are arguments which relate to the nature of the doctor-patient, or hospital-patient relationship.

A. Democratic Principles

Freedom of information legislation is generally justified in terms of the requirements of a truly democratic system of government. Perhaps the essence of democratic government is that it is ultimately accountable to the public. It is the public who decide who shall govern and how best the country is to be governed. For decisions to be made properly, the public must have access

to the relevant information. Access to information legislation is one way of securing the necessary means for obtaining such information.

Secondly, it can be argued that democratic government is vested with the responsibility of promoting individual rights. There is increasing acceptance of the view that individuals have a right to see files maintained by government, especially if the files contain information personal to the individual concerned. In the hospital situation the patient has a right to authorise disclosure. One might well ask how this concurrent right can be exercised when the patient has no way of knowing what is on the record. It might also be argued that such a right of access exists simply because it contains highly personal information. It has been suggested that the medical record is part of the self i.e. it is an extension of the personality, and, as such, denial of direct access may be tantamount to a confiscation of self or even analogous to false imprisonment [18].

B. The Practical Benefits of Direct Access

One way of identifying such practical benefits is to examine recent research in the area of access to medical records.

One of the most comprehensive pieces of research was undertaken by Golodetz [19] who attampted to assess the effects of giving patients in a sixteen bed unit of the Medical Center Hospital of Vermont carbon copies of their medical records. Since 1972 all patients in the unit had been given copies of their records with the following aims in mind:

1. -to improve patient education.
2. -to improve the patients chances to contribute to the planning of his care.
3. -to increase the staff's accountability to the patient.

The results of the assessment were summarised as follows:[20]

> "in 10% of the records modifications were made by the physician because he knew the patient was going to read it. In only one case was the modification one concerning fact, and that was when material had been communicated by the patient's spouse in confidence.
> - 84% of patients expressed a strong desire to be well informed about their condition.
> - 50% of patients made some addition or correction on a point of fact.
> - 60%asked questions on vocabulary or meaning.
> - 72% of patients preferred access to medical records as a means of being informed.

- 22% preferred a summary.
- 4% preferred discussion only.
- the patients used the records to explain their condition to their families."

Golodetz also attempted to assess the effect of the programme on members of the staff and came to the following conclusions:[21]

"- initial staff fears were soon dispelled.
- each member could interact more freely and honestly with the patient.
- there was a move from paternalistic and caretaking relationships to more collaborative and educational ones."

The general conclusion reached was that:[22]

"Record-sharing is a tool that may serve to improve patient's satisfaction with their medical care. It may increase the ability of patients to care for themselves and to move about within the medical-care system in an orderly way. It may prove to be one of audit for quality and efficiency of care. We conclude from the results of this study that the procedure is feasable and worthy of further evaluation."

Dr Golodetz, who headed the above research programme was quoted as saying:[23]

"Patients in general tend to complain they don't know what their doctors are thinking or why things are being done to them. The fact of ignorance is often demonstrated by non-compliance with instructions. In any situation including chronic illness or disability the patient needs to be involved."

Similar positive results have been identified at Berlington Hospital in Vermont[24]. Patients in that hospital have been given copies of their medical records since 1973. Physicians in the hospital were reported as saying:[25]

"the practice stimulates co-operation, does not harm patients and reduces their anxiety."

The article also mentioned that of the 8,000 patients who had received copies of their medical records, 93% felt the procedure had reduced their anxieties about their health.[26]

One last piece of research which is worth mentioning is one which was undertaken in a Washington psychiatric hospital

The study attempted to assess the effects of the Privacy Act 1974. The Act, which will be discussed later, provides for a right of access to medical records held by federal agencies. St. Elizabeths Hospital is a federally run mental hospital in Washington D.C. and as such, was required to establish procedures through which patients could review and appeal the content of their medical records. Some of the more important findings were summarised as follows:[27]

> "only 2%of the 5,000 patients requested access to their records, all of which were granted.
> - only 5 patients requested amendments to their records, two of which were approved
> - patients who fully completed the review process reported they felt little or no different about themselves or staff members after reading the record
> - several reported that the information they read was trite, or that they could not understand the content.

The conclusion to be drawn from these studies is that the reality of patient access to medical records is a far different reality from that which is suggested by the arguments used to support present policy. The study undertaken at St. Elizabeth Hospital is perhaps most relevant since a mere right of access was acknowledged, as oppossed to the automatic giving of records which occurred in the other two hospitals. The most significant result of the study was the finding that so few people exercised their right of access. This does not detract from the worth of such a right, but simply points out that such a right of access is not necessarily a disruptive and administratively unworkable thing. The other two studies are important in that they identify many positive results from providing access to medical records. The results also dispell the fears that the patient's best interests will not be served by providing for a right of access.

It is submitted that in addition to these theraputic benefits, providing for a right of direct access in the hospital situation may help free up the availability of medical information held by other welfare institutions. For example, the policy of non-disclosure which is maintained by the Department of Social Welfare and the Accident Compensation Commission may in part be a result of deference to the attitudes held by the medical profession. Once direct access is introduced into the hospital situation, there will be little basis to deny access in these other areas.

C. The Doctor - Patient Relationship

There are a number of principles which regulate the doctor-patient or hospital - patient relationship. It is worthwhile giving some consideration to these principles. It is possible that they may support a right of direct access, or alternatively, such a right might further the aims which these principles attempt to promote.

1. The Doctor as a Fiduciary

The fiducial nature of the doctor - patient relationship imposes an obligation on the doctor to act in the interests of the patient. It is submitted that in many cases it might be in the best interests of the patient to have direct access to his medical record. The case of Emmett v. Eastern Dispensary and Casualty Hospital [28] was one in which the plaintiff alleged the hospital had negligently caused his father's death. Prior to bringing the action the plaintiff had attempted to gain access to his father's medical record. The hospital had refused, and, because of the delay which resulted the action was threatened by a one year time limit imposed by local legislation on the bringing of such an action. The plaintiff stated he was able to get into court within the one year period because of the defendant's action in refusing access to the deceased's medical record. The court, in waiving the one year limitation required stated:

> "We find in the fiducial qualities of the doctor - patient relationship the physician's duty to reveal to the patient that which in his best interests it is important that he should know. And we would consider anomalous in this age any rule that would immunize from a similar obligation a hospital which is the repository of such knowledge." (p.935)

Admittedly, the court did not recognise an unrestricted right of access, but limited the duty to situations where access was in the patient's best interests. It is submitted that the decision is simply in accordance with the notion that a right of access to medical records might need to be subject to exceptions. The point remains that where denial of access is against the best interests of the patient, it can be argued that the hospital is in breach of it's fiducial obligations.

2. Informed Consent

A fundamental principle underlying the doctor - patient relationship is that of informed - consent. It requires that

the patient gives his consent to any proposed treatment, and does so in an informed way i.e. he must be so informed that his consent is based on a reasonable assessment of the type of illness he is suffering from the procedure involved in treating such illness and the nature and extent of the risks involved in undergoing such treatment. The principle is of such importance that it has been incorporated into various Codes of Rights. The Wellington Hospital Board Code of Rights lists twelve rights which a patient is entitled to. Nine of those rights involve exclusively or in part, the right to have access to information. For example, the third right provides: [29]

> "Patients are entitled to be told as much as they want to know about their illness, their course of treatment and likely outcome, by the doctor responsible for their care."

Although patient access to medical records is not a prerequisite for the operation of the principle of informed consent, it is submitted that providing a right of access is in keeping with the notions of openness and the free flow of information which are inherent in the principle of informed consent. The provision of such a right may also contribute to the breakdown of barriers which at present inhibit full compliance with the principle of informed consent. The assertion that the principle has not been adequately complied with gains support from a number of recent studies. In 1979 Dunkelman [30] undertook a study in a London hospital to access how much patients knew about their condition and treatment. She found that half the patients were apparently ignorant of the nature of their operation and why they were being performed, even though they had consented to undergo them. She recommended that patients should be told more about matters relating to their condition and treatment and that written information could be given to supplement information given orally. Parkin in 1976 [31] found that only fifty percent of discharged patients from a London hospital knew their own diagnosis while less than thirty percent could identify the drugs they were taking or why they were taking them. In the Steiner [32] study on physician attitudes, respondents were asked to rate the general medical knowledge of their patients. Fifty percent felt that such knowledge was only "fair". It is perhaps also worth noting that twentyeight pepcent of the responding physicians felt that patients should have access to part or all of their medical records.

It must be recognised that providing a right of access is passive and will not give rise to a situation where all patients will be reading their records. Only two percent exercised

their right of access in the St. Elizabeth Hospital study.[33] However, it may be that providing a right of access may act as a catalyst in prompting hospitals to adopt a more open approach to providing patients with information. A number of hospitals in America have a policy of automatically providing patients with copies of their medical records.[34] These programmes may in part have arisen out of the principles and values underlying the various pieces of legislation providing for access to information.

3. Property Rights

It is submitted that the concept of "property" is inappropriate for dealing with the question of a patient's right of access to his medical record. The two American cases[35] which asserted such a property right in the information contained on the record made no attempt to explain the origins of such a right.

Property rights are typically acquired by contract, by succession, by occupancy or by invention and creation. It is submitted that there is a difficulty in arguing that a patient has performed any such act which confers upon him a property right. In fact the very opposite has occured. It is the hospital staff who have obtained the information who have exercised their skill in interpreting facts and formulating opinion.

There is a similar difficulty in establishing a property right on the basis of the contract which exists between hospital and patient. It is submitted that the contract is one of service and labour and in the absence of property acquiring action by the patient the courts would be reluctant to imply a condition into the contract conferring such a right. Support of this view comes from the English cases[36] already referred to which have consistantly refused to recognise a property right to such information.

However, the inapplicability of traditional legal concepts is far from being fatal to the thesis of this paper. The right of access to information is a new kind of right which has arisen from emerging ideas about the direction which democratic societies should be taking. It's justification rests on the readiness of society to accept it, not necessarily the applicability of existing legal concepts.

V. THE OVERSEAS RESPONSE

In the United States both the Freedom of Information Act 1967[37] and the Privacy Act 1974[38] provide individuals with various rights of access to information. The Freedom of Information Act 1967 exempts from disclosure[39] "personnel and medical files ... the disclosure of which would constitute a clearly

unwarranted invasion of personal privacy. A number of agencies appeared to have refused individuals access to their medical records on the grounds that it was an invasion of personal privacy.[40] This anomaly was in part corrected by the Privacy Act 1974, which provided for a persons access to:[41]

> "files held by the Federal Government in his/her name under an identifying number symbol or characteristic belonging to him or her."

Although medical records were not exempt from the general right of access provision was made so that agencies could establish procedures for disclosure. The Act provides that,[42]

> "In order to carry out the provisions of this section, each agency that maintains a system of records shall promulgate rules... which shall ... establish procedures for the disclosure to an individual, upon his request, of his record or information pertaining to him, including special procedures, if deemed necessary, for the disclosure to an individual of medical records, including psychological records pertaining to him."

The phrase "special procedures" has been interpreted so as to permit procedures which enable the agency to withhold information which would adversely effect the applicant.[43] The interpretation seems to have been warranted in view of the legaslative history of the provision, which has been quoted at follows:[44]

> "If in the judgment of the agency the transmission of medical information directly to a requesting individual could have an adverse effect upon such individual, the rules which the agency promulgates should provide means whereby an individual who would be adversely effected by receipt of such data may be apprised of it in a manner which would not cause such adverse effects."

The response of one hospital in Washington D.C. was to establish procedures whereby the clinical superintendant had 30 days to review a record and could modify direct access by deleting certain portions of a record.[45]

As well as the Privacy Act 1974, nine states have legislation providing for access to medical records. Colorado[46] which had the most liveral statute, grants the patient the right to obtain a copy of his record without resort to litigation and without

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the authorisation of physicians or hospital officials. The right extends to records kept by both state and private hospitals as well as those kept by private physicians, psychologists and psychiatrists. The right to psychiatric records is limited to ex-patients. Florida [47] on the other hand, gives the patient the right to obtain copies of examination and treatment reports, but makes no mention of hospital records. Connecticut,[48] Indiana, [49] Louisiana [50] and Massachusetts [51] deal only with hospital records while Mississippi[52] and Tenessee [53] require the patient to show good cause before he will be granted access to his medical record.

Since the Privacy Act 1974, there have been moves in the United States to enact legislation dealing specifically with the protection of medical records. The Privacy Protection Study Commission was set up in 1974 to examine individual privacy rights in many contexts. In it's 1977 report the Commission recommended:[54]

> " That each State enact a statute creading individual rights of access to, and correction of, medical records, and an enforceable expectation of confidentiality for medical records ..."

In addition the Commission urged;[55]

> "that such statutes create a limitation of liability to protect the medical - care provider against actions brought for defamation, invasion of privacy, or negligence when a medical record or medical record information is released pursuant to the requirements of the statute..."

In response to this recommendation, the Committee on Governmental Affairs was delegated with the responsibility of designing legislation to protect the privacy of medical records. The testimony which has been presented to the Committee has been overwhelmingly in favour of providing patients with a right of access to their own records. [56] It should be noted that the legislation contemplated goes beyond the rights conferred by the Privacy Act 1974, in that the right extends to all medical care providers, federal, state run or private.

Freedom of Information legislation is at present being considered in Canada, Australia and the United Kingdom. None of the Bills in question have excluded medical records from the general right of access. [57]

VI. LEGISLATIVE SOLUTION

A patient's right of direct access to his medical record could be provided for within the contect of an all encompasing Freedom of Information Act, or more specific legislation dealing exclusively with access to medical records. It may even be appropriate to incorporate the necessary provisions into the Hospitals Act 1954, which already deals with some aspects of the patient's privacy rights in relation to his medical record.[58]

It is submitted that either of the latter two approaches are the most appropriate. The first approach, which tends to be general in nature, is typically limited to state run agencies. There are 158 private hospitals in New Zealand, catering for 5119 patents.[59] There is no reason in principle why these patients should be denied the rights accorded to patients in state run hospitals.

Another disadvantage of the general approach is that is may be incapable of dealing with specific aspects of access. For example, the United States Privacy Act 1974 has dealt superficially with medical records, leaving questions of procedure and exemptions to the individual agencies by conferring a power to promulgate rules.[60] Special procedures may be formulated for medical records. This rule making power if adopted here could well lead to a wide range of different procedures being adopted by each hospital. It is submitted that this lack of consistency is inappropriate for legislation which is attempting to deal with basic human rights. Rights are not something which should fluctuate from situation to situation.

Whichever format is adopted, there are a number of issues which must be dealt with by access legislation. Scope, exceptions and access procedure are three issues which deserve consideration in relation to medical records.

A. Scope

In general, legislation which confers a right of access to information does so by granting a right of access subject to a certain number of exceptions. The right of access typically entails a number of supplementary rights, for example, the right to photo-copy the record and the right to challenge the accuracy of any information. This right to challenge necessarily involves the right to have incorrect information deleted or corrected. These concurrent rights are perhaps nowhere more important than in the contect of medical records. The medical record is continually used by the hospital as an aid in treating the patient. The quality of such treatment in part depends on

the accuracy of information contained in the record and the right to challenge or correct may be an added measure of quality control.

The question also arises as to whether the scope of such legislation should extend to psychiatric hospitals. It is submitted that an adequately drafted exception provision would make such legislation equally workable within the psychiatric hospital. If the exception provision can't be invoked, then the psychiatric patient should not be denied access. It may be, however, that the exception is more often invoked, but if it is not, why deny access?

B. Exceptions

Perhaps the most difficult question to be answered in formulating such legislation is whether the general right of access should be absolute or whether it should be qualified by exceptions.

On the one hand, it could be argued that access should be absolute. After all, persons sui juris are supposedly vested with the responsibility of controlling their own destiny. This is one of the very assumptions which underly the principle of informed consent. It presupposes that individuals are capable of dealing with their personal circumstances. It may be that knowledge of one's fatal condition will enable important decisions to be made. For example, a terminally ill patient may not wish to be kept alive by artificial means, or it may be that treatment has adverse side effects which the patient would rather do without, especially if the treatment is merely extending the patient's life expectancy by a few weeks. It could also be argued that a patient who requests access will have considered the possibility that the record may contain disturbing information, and the fact that the request is made, shows a willingness to accept the consequences.

On the other hand, the fact remains that some people may simply not be able to cope with certain kinds of information. In a number of United States decisions the courts have been mindful of the danger of disclosing potentially harmful medical information and have developed what has come to be known as "therapeutic privilege". The principle has developed within the context of informed consent and operates as a defence to allegations that sufficient information was not given to the patient. The general rule was stated by the California Supreme Court in Cobbs v. Grant [61] where the court stated:

> "A disclosure need not be made ... when a doctor can prove ... that the disclosure would so seriously upset the patient that the patient would not be able to dispassionately weigh the risks of refusing to undergo the recommended treatment."(p.516)

A similar rule was proposed in the case of Canterbury v. Spence,[62] although the court further stated that when the physician invoked the defence, he or she should be required to disclose the information to a close relative.[63]

It is submitted that the rules emerging from these two cases could form a satisfactory basis for formulating an exception provision, i.e. the hospital would have the power to withold information on the medical record if, in their opinion, it would be injurious to the patient. In such a case, however, the hospital would be obliged to disclose to a responsible third party. A similar solution was proposed by the Privacy Protection Study Commission in their 1977 report.[64] They stated:

> "no solution would be acceptable in the long run so long as it risks leaving the ultimate discretion to release or not to release in the hands of the patient's physician. In situations where the keeper of a medical record believes that allowing the patient to see and copy it may be injurious to the patient, the Commission concluded it would be reasonable for the record to be given to a responsible person designated by the patient with that person being the ultimate judge of whether the patient should have full access to it. In no case, however, should the physician or other keeper of the record be able to refuse to disclose the record to the designated responsible person, even where it is known in advance that the designated person will give the patient full access to it."

It is submitted that a provision based on this format is one way of obtaining a balance between the rights of the individual to have as great an amount of access as possible while still retaining an avenue whereby potentially harmful information can be excluded from direct access. Of course, this suggestion does face a number of obstacles. For example, who is to decide whether the third party nominated by the patient is a "responsible" third party and who is to decide what information

comes within the exception? It is submitted that these difficulties can be resolved by establishing a satisfactory procedure for access.

C. Access Procedure

It is submitted that initial decisions as to whether information should be directly disclosed or whether it comes within the provided exception should be made by the hospital administration. As long as an adequate system of appeal and review exists, this would be the most administratively pragmatic approach. A mechanism allowing for internal review of a decision may also be desirable. Such a mechanism would possibly dispose of what might otherwise require the implimentation of a more formal and time consuming appeal procedure. However, without an adequate avenue for external appeal, the hospital administration may be tempted to exercise it's discretion in the light of self interest rather than the patient's interest. The point that must be made in relation to an appeal structure which relates to access to medical records is that the members of the appeal authority must be capable of making a decision as to what information is likely to be detrimental to a patient. The question is very much a medical one, although it will require a weighing up of the advantages to be gained by securing access. The short point is that the appeal authority must either consist of members who are qualified to make such an accessment, or must be empowered to call on persons who are suitably qualified to make appropriate recommendations.

CONCLUSIONS

At present, patients in New Zealand hospitals are denied direct access to their hospital medical records. This paper has attempted to show that the reasons which support present policy are largely illfounded and, at the most, support the notion that exceptions to a right of access may be required. With increasing demands for open government and the establishment of legislative protection for basic human rights it has been suggested that patients have a statutory right of access to their medical records. Such a right of access should also enable the patient to obtain a copy of his record as well as have incorrect information deleted or corrected. It has been recognised that the hospital should be able to withhold information it considers will be detrimental to the patient, although access should be allowed to a responsible third party nominated by the patient and any decision should be subject to review and

appeal. Such safeguards should discourage hospitals from invoking the exception provisions as a result of self-interest.

Similar legislation has operated successfully in the United States , and, if introduced into New Zealand, would be one way of giving effect to the right of access to information, a right which has now gained considerable support in democratic societies.

FOOTNOTES

1. R.Prebble's Freedom of Information Bill 1977
2. Case W12873 1979 Annual Report of the Ombudsman
3. Leicestershire County Council v. Michael Faraday and Partners Ltd. [1941] 2K.B. 205 at 216
4. London School Board v. Northcroft 1889 Hudson's Building Contracts, 4th ed. Vol. 2, 147
5. Gotkin v. Miller 379 F. Supp. 859 (1974).
6. Ibid. 514 F. 2nd 125 (1975).
7. Wallace v. University Hospital of Cleveland 164 N.E. 2d. 917 (1959)
8. Pyramid Life Insurance Co. v. Masonic Hospital 191 Fed. Supp. 51 (1961).
9. Interview with Assistant Medical Superintendant Wellington Hospital 16.5.80.
10. refer p. 13
11. refer p. 14
12. Information Access and the Workers Compensation Board. T.G. Isan. Research Publication (Can.) 1979
13. Seitz et al. "Granting Patients Access to Records : The impact of the Privacy Act at a Federal Hospital" Hospital and Community Psychiatry 29:5 at p.288 (1978)
14. Hayt and Hayt. Law of Hospital, Physician and Patient. Berwyn, Ill. 1972 at p.652
15. refer p.10 et seq.
16. Ante, note 13 at p.288
17. Steiner P. "Patient Access to Medical Records : A Study of Physician Attitudes. Med. Rec. News Aug. 78 at p.77
18. Ante, note 12 at p.88
19. A. Golodetz M.D. et al. "The Right to Know" Archives of Physical Medical Rehabilitation. Vol 57 at p.78 (Feb.1976)
20. Ibid. at p.79
21. Ibid. at p.80
22. Ibid. at p.86
23. Author unknown "How to reduce Patients Anxiety : Show them their hospital records. Med. World News. Vol 16 (Jan 1975) at p. 48
24. Ibid. at p.48
25. Ibid. at p.48
26. Ibid. at p.48
27. Ante, note 13 at p.289
28. Emmett v. Eastern Dispensory and Casualty Hospital 398 F. 2d. 931 (1963)
29. Wellington Hospital Board Code of Rights - Pamphlet published by Wellington Hospital Board

30. Dunkelman. "Patients Knowledge of their Condition and Treatment" Brit. Med. Journal. 4 Aug. (1979) at p.311
31. Parkin D.M. "Survey of the Success of Communications between Hospital Staff and Patients" Pub. Health 90:5 (1976) at p.203
32. Ante, note 17. at p.78
33. Ante, note 13 at p.288
34. refer p.10 et seq.
35. Ante, note 7 & 8
36. Ante, note 3 & 4
37. 5 U.S.C. 552
38. 5 U.S.C. 552a
39. 5 U.S.C. 552b (6)
40. Personal Privacy in an Information Society. The Report of the Privacy Protection Study Commission July 1977 at p.508
41. 5 U.S.C. 552a (d)
42. 5 U.S.C. 552af (3)
43. Ante, note 13
44. Ante, note 40 at p.297
45. Ante, note 13
46. Colo. Rev. Stat. 25-1-801
47. Fla. Stat. Ann 458.16
48. Conn. Gen. Stat. Ann. 4.104 (1969)
49. Ind. Code Ann. 34-3-15-5-4
50. La. Rev. Stat. Ann. 44.31 (1951)
51. Mass. Gen. Laws Ann. ch.111 70 (1971)
52. Miss. Code Ann. 7146-53 (Supp.1971)
53. Tenn. Code Ann. 53-1322
54. Ante, note 40 at p.293
55. Ibid. at p.294
56. Hearings before Committee on Governmental Affairs. U.S. Senate Ninety-sixth Congress. 1st session on S.503 and S.865 June 27 Aug. 3 Nov. 13 1979
57. See: Australian Freedom of Information Bill 1978, Canadian Freedom of Information Bill 1977, U.K. Freedom of Information Bill 1979
58. Hospitals Act 1957, S.62
59. New Zealand Yearbook 1979
60. Ante, note 42
61. Cobbs v. Grant 104 Cal. Rpts. 505 (1973)
62. Canterbury v. Spence 464 F.2d. 772 (1972)
63. Ibid. at p. 789
64. Ante, note 40 at p. 298

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