Use of Personal Health Information by Third Parties for Research Purposes

Susan Keppel

I: INTRODUCTION

The volume, private nature and mobility of information contained in personal health records raises concerns as to the use of personal health information without consent. This article examines the use of personal health information by third parties for research purposes. In particular, it examines the fiduciary relationship between doctor and patient, and the possible remedies available in the event of any breach of this relationship. The article reviews the protections available to the various parties involved, including researchers. Attention is focused on the importance of achieving a balance between the needs of society in relation to medical research and the rights of the individual. To this end, recommendations are made as to the specific measures required in order to accord adequate protection to all the parties involved.

By way of introduction, the article canvasses the nature of health records and the protection historically afforded to them. It also outlines the importance of health records in relation to ongoing medical research. The concepts of privacy and confidentiality are examined, as is the public interest factor in medical research.

II: USE OF PERSONAL HEALTH RECORDS FOR RESEARCH

1. Nature of Health Records

Personal information may be defined as "those facts, communications or opinions which relate to the individual and which it would be reasonable to expect the individual to regard as intimate or confidential requiring the withholding or at least the restriction of their circulation".[1] The British Medical Research Council[2] has defined medical records as comprising all recorded observations relating to identifiable individuals made in the context of:

(i) health and medical care;
(ii) medical research;
(iii) other circumstances in which information is given to a doctor in his/her professional capacity; and
(iv) other situations in which medically relevant information is recorded, such as a claim for a sickness benefit – these records may at times include data which are confidential but which are not strictly medical.

Historically, the personal information contained in health records has long been regarded as resulting from a relationship of trust, thereby attracting the protection of confidentiality. The confidential relationship between doctor and patient is enshrined in the Hippocratic Oath:

> Whatever, in connection with my professional practice, or not in connection with it, I see or hear in the life of men, which ought not to be spoken of abroad, I will not divulge as reckoning that all such should be kept secret.

Modern reformulations of the Hippocratic Oath, such as the Declaration of Geneva,[3] reaffirm this confidential relationship:

> I will respect the secrets which are confided in me, even after the patient has died.

However, Hippocrates could never have been aware of the sophistication or potential of modern medicine, nor of the development of communication systems. He would also have been unaware of the scale of problems that confront medical and scientific researchers today. The information contained in modern medical records is complex and multi-sourced and may include information about people other than the patient such as, for example, family members.

Information contained in health records has the capacity to be more intensely personal and all-encompassing than any other collection of data. Routine medical

---

1 Wacks, *The Protection of Privacy* (1980) 22.

2 The Medical Research Council, "Responsibility in the Use of Medical Information for Research" Br Med J 1973; 1: 213-216.

3 Brazier, *Medicine, Patients and the Law* (1987) 32.

information includes name; address; age; date of birth; occupation; medical, surgical and psychiatric history, including previous hospital admissions; past and present family history; social circumstances; contraceptive use and abortion history; and the use or abuse of alcohol and medications. Information may also be recorded on peripheral areas that impact on health such as violence, sexual abuse, financial difficulties, marital problems and sexual preferences. This information may become particularly detailed if reports from specialists, social workers or others are obtained.

An increasing number of general practices store patient information in computer systems. The advancement of computerised technology alone need not necessarily sound alarm bells for the cause of confidentiality and privacy; manual systems are also far from perfect. Indeed, computerised systems with safeguards such as restricted access for certain personnel and the use of passwords have the potential to be very secure, although absolute security is impossible.

Public hospitals within the Auckland Area Health Board have traditionally used manual systems for health records but this will soon change with the purchase of a new computerised system. This system will begin by storing small amounts of non-medical data, such as demographic details, which will be added to incrementally so that within approximately four years all patient health data should be included. Health information is also stored in a variety of other places, such as private hospitals and pathology laboratories.

There is, then, a large pool of information which is not only valuable to the individuals concerned but also to medical researchers seeking a solution to wider problems.

2. Role of Health Records in Research

With the proposed introduction of privacy legislation in New Zealand, it is appropriate to examine the position of health records in relation to research. Professor Ian Kennedy, identifying the four areas (apart from AIDS) of persistent and increasing difficulty for the 1990s, named one as involving confidentiality, access to information and privacy; and another as the issue of consent in all its forms.[4] Both these areas impact on the use of health records for research, particularly when informed consent, with its requisite elements,[5] is not obtained. In practice, a distinction has long been made between research embodying experiments that interfere with people, and non-experimental research in which knowledge is gained by studying records.[6]

Personal information is routinely collected, disclosed and acted upon in health

---

4 Kennedy, *Medical Law in the 90s*, paper presented to 9th Commonwealth Law Conference, Auckland 1990.

5 New Zealand Health Council Working Party on Informed Consent, *Informed Consent* (1989) 25.

6 Medical Research Ethics Committee, [Australian] National Health and Medical Research Council, *Report on Ethics in Epidemiological Research* (1985) 10.

care.[7] The systematic collection and analysis of medical information has always been an important requirement, especially for those concerned with the study and control of the health of the whole population, rather than the individual patient. Improved understanding of disease, which may lead to control and prevention, often results from recording events in the lives of a large number of patients. Thus, the results of such studies can contribute greatly to health planning and to more effective allocation of resources.

The examination of health records for research is normally done without the explicit consent of the individual patient. Thus records are being utilised for a purpose other than their original purpose, or at least for a purpose other than the original purpose that most patients would acknowledge. Yet medical research has traditionally been highly valued by society, and indeed by most individual people.

There is clearly a conflict of interest between the rights of patients to the privacy and confidentiality of personal medical information, and the public interest in continuing medical research. On this basis, the legal issues pertaining to the rights of an individual to privacy and confidentiality cannot be examined in isolation. There must also be understanding and acknowledgment of the objectives and the benefits derived from those areas of medical research which rely on disclosure of personal health information, and recognition of the practical difficulties confronted by such researchers. It is therefore proposed to examine this conflict of interest in the context of two examples of medical research which are dependent on the dissemination of patient information: those of cancer registration and epidemiological studies. The objectives, benefits and practicalities of these studies are outlined below.

Cancer registration

In 1987 cancer caused 23% of all deaths in New Zealand.[8] It causes a greater loss of potential years of working life than any other cause of death – including heart disease and road accidents. Cancer is the only major cause of death that is continuing to increase.[9] In spite of this, New Zealand does not have a satisfactory national programme for cancer control aimed at reducing mortality and morbidity from cancer, increasing the rate of cure and improving the quality of life for people who survive cancer.[10] Unfortunately the Cancer Registry in New Zealand functions inadequately and is unable to play its full part in cancer control.

One important factor contributing to this problem is the cessation of referral of patient names by private pathologists in Auckland since 1985. This decision was

---

7 Berglund, "Australian Standards for Privacy and Confidentiality of Health Records in Research: Implications of the Commonwealth Privacy Act" Med J Aust 1990; 152: 664-669.

8 National Health Statistics Centre, *"Mortality and Demographic Data 1987"* (1989) Department of Health.

9 Skegg, "Losing the Battle Against Cancer" NZ Med J 1989; 102: 214-215.

10 Ibid, 214.

made by pathologists due to the inadequacy of legal safeguards. The pathologists were not prepared to incur the risk of liability in relation to the disclosure of confidential information.[11]

According to the International Agency for Research on Cancer, a registry is an essential part of any national programme of cancer control. A cancer registry is an organisation which collects, stores, analyses and interprets data on people with cancer. It can provide information that is useful in identifying the causes of cancer, in designing prevention and screening programmes, in planning for cancer services, and in monitoring the results of treatment.[12]

In practical terms, the aim of the New Zealand Cancer Registry is to hold a record of everyone in New Zealand who suffers from cancer. As a consequence, mechanisms are in place to collect all relevant information from such diverse sources as public hospitals, private hospitals and laboratories, death certificates and autopsy reports. Information that identifies the patient is essential, as otherwise duplicates could not be eliminated and the incidence data would be worthless. Further information, such as race and occupation, permits detection of groups with a high risk of cancer, while recording deaths permits estimates of survival time.

One function of the cancer registry is to provide information to individual researchers. Data from the Cancer Registry may be used by a variety of research specialists examining cancer-related problems. This information can be provided without identifiers, or with data leading to personal identification of the patient (which may be needed if the researcher wishes to obtain further information from the patient or relatives). Data in the latter category would require the approval of an appropriate ethical committee.

In summary, the New Zealand Cancer Registry contains a valuable store of information relating to cancer, all of which is personal information about individually identified people, and which is made available to researchers for the purpose of studying various forms of cancer.

Epidemiological research

Epidemiology may be defined as the study of the distribution and determinants of disease in human populations.[13] Its purpose is to understand the natural history of disease and to develop and evaluate strategies for prevention. While traditional clinical medicine focuses on the treatment of the individual, epidemiology is concerned with gathering information from large numbers of individuals in order to ascertain general trends and effect health changes within population groups. Information from many individuals is used to provide knowledge which can benefit many other people. Epidemiological research depends on the availability

---

[11] See text, infra at pp14-15 for a discussion relating to the legal issues arising.

[12] See Cancer Registration Working Group, *Cancer Registration in New Zealand* (1988).

[13] Christie, *Epidemiology: An Introductory Text for Medical and Other Health Science Students* (1987) 1.

of medical records of large numbers of people for the data they contain, and to identify individuals for subsequent interview upon obtaining their consent. Information identifying individuals is essential not only to enable patients to be interviewed and studied, but also to link records on a given person from different sources and to compare groups of patients who have a disease with those who do not.[14]

Epidemiologists consider it impracticable to acquire individual consent before examining patients' notes. This is because it is considered inappropriate to obtain a generalised consent in relation to the examination of medical records, and researchers would only become aware of some cases in retrospect. In such circumstances, they would often encounter insurmountable difficulties in seeking to trace patients after the event in order to obtain consent for access to the relevant notes. Such gaps in the cases identified would be sufficient to render the entire epidemiological programme invalid.

Major contributions to the understanding of disease have resulted from epidemiological studies. Recent examples of epidemiological studies demonstrate:[15]

(i) the relationship of cigarette smoking to lung cancer, coronary heart disease and stroke;
(ii) increased cancer risk associated with occupational exposure to asbestos;
(iii) that women taking oral contraceptives are at increased risk of developing thromboembolism or stroke;
(iv) that cases of polio which developed subsequent to polio immunisation in 1955 resulted from a vaccine lot having been contaminated with live virus;
(v) that administration of high concentrations of oxygen to premature infants causes blindness; and
(vi) that maternal rubella infection during pregnancy produces congenital malformations in the infant.

Furthermore, epidemiological evidence was primarily responsible for the recent landmark Australian decision in which an injunction was granted enjoining the respondent from publishing any future advertisements which stated that there was little evidence, and nothing which proves scientifically, that cigarette smoke causes disease in non-smokers.[16]

---

[14] Gordis et al, "Privacy Protection in Epidemiologic and Medical Research: A Challenge and a Responsibility" Am J Epidemiol 1977; 105: 163-168.

[15] Ibid, 165.

[16] *Australian Federation of Consumer Organisations Inc v Tobacco Institute of Australia* (1991) 98 ALR 670.

Current investigation into cardiovascular disease

While the above examples are broader illustrations of the results of epidemiology, it is also appropriate to refer to a current study investigating cardiovascular disease.[17] This study originally established a register of patients with myocardial infarction and cerebrovascular disease, with the former being maintained on an ongoing basis. Routine sources of case finding include systematic searches of public hospital admission lists, the checking of death certificates, and initially inviting a random sample of Auckland general practitioners to refer to the study all patients suffering a coronary or stroke who were treated out of hospital.[18]

Once identified to the study, patients or relatives of dead patients are able to be approached by the study group and may be interviewed if they consent. Patients are able to be studied at intervals as required. As a result, an enormous base of information is obtained which enables the trends and determinants of coronary heart disease to be monitored. This type of information is particularly important in planning future strategies for disease control[19] and examining the effectiveness of existing facilities and services.[20] The study is approved by the University of Auckland Human Subjects Ethics Committee. The coronary component of the study has become part of a World Health Organisation collaborative study which monitors cardiovascular disease in twenty-seven countries around the world.

III: CONFIDENTIALITY AND PRIVACY VERSUS PUBLIC INTEREST

In light of the above examples of the benefits that can result from the use of personal information without individual consent, what then are the issues for the patient who gives information to his or her doctor in the belief that it will not be disclosed?

1. Confidentiality and Privacy

Confidentiality and privacy are separate but related issues. The Australian Law Reform Commission noted that the term "privacy" is one fraught with difficulty and chose to give it an ordinary usage meaning, that which it has in everyday language.[21] The ordinary usage is illustrated by the example of a person who, when asked why it is offensive to have his or her premises searched, replies "Because it

---

[17] Auckland Region Coronary or Stroke Study, Departments of Medicine and Community Health, University of Auckland. This study has been established for a period of ten years.

[18] Bonita et al, "The Long-Term Monitoring of Cardiovascular Disease: Is it Feasible?" Community Health Studies 1983; VII: 111-116.

[19] Beaglehole et al, "Prevention and Control of Hypertension in New Zealand: A Reappraisal" NZ Med J 1988; 101: 480-483.

[20] Bonita, "Rehabilitation Services Received by Stroke Patients: The Auckland Stroke Study" NZ Med J 1988; 101: 595-597.

[21] Australian Law Reform Commission, *Privacy* (1984): see Vol 1, 11.

invades my privacy." Privacy recognises the individual's autonomy and integrity which is fundamentally respected by the common law.

Confidentiality, on the other hand, protects privacy. The duty to maintain a confidence is a limited remedy for the invasion of a more general principle, the right to privacy.[22]

Legal duty to maintain confidence

The notion of confidence as the relationship of intimacy or trust between two persons, one of whom has imparted private or secret matters to another, has been present for centuries and has been recognised in English law since at least the early nineteenth century.[23] A breach of confidence action offers protection against violations of one's privacy. It enables the confider to control the dissemination of personal information by others to whom he or she has entrusted the information.

The jurisdictional basis of the action for breach of confidence has been a source of lingering uncertainty.[24] Relief could be provided through contract, equity, tort, or very rarely, proprietary rights,[25] with different remedies depending on the basis of the action. In order to establish a cause of action, Gurry notes that the confider must satisfy three requirements:[26]

(i) the confider must show that the information he or she has imparted was confidential. As a general rule this is done by showing that the information is inaccessible to the public. The test for inaccessibility most often used by the courts is that established by Lord Greene MR assessing whether special labours were necessary to reproduce the information;[27]

(ii) the confider must establish that the confidential information was disclosed in circumstances that imposed an obligation on the confidant to respect the confidentiality of the information; and

(iii) the confider must show that the confidant has made an unauthorised use of the information.

Laster suggests that the touchstone for breach of confidence is whether trust can be found to have been reposed in, and accepted by, the recipient of the information.[28]

In the recent English case of *X (Health Authority) v Y*,[29] Rose J held that

---

22 Rayner, "Confidentiality of Patient Identifiable Data" Aust Med Rec J 1990; 20: 12-17. Ms Rayner is Chairperson of the Law Reform Commission of Western Australia.

23 Laster, "Breaches of Confidence and of Privacy by Misuse of Personal Information" (1989) 7 Otago LR 31, 32.

24 Gurry, *Breach of Confidence* (1984) 25.

25 Ibid, Chapter II.

26 Ibid, 4.

27 *Saltman Engineering Co Ltd v Campbell Engineering Co Ltd* [1963] 3 All ER 413, 415.

28 Supra at note 23, at 39.

29 [1988] 2 All ER 648.

detriment is not a prerequisite for breach of confidence. The media defendant was enjoined from publishing the fact that two unidentified doctors were suffering from AIDS, notwithstanding the fact that publication would result in no detriment to the plaintiff hospital board. The case also recognised the broader interests of the hospital in encouraging honesty and trust in its relations with patients. In *Attorney-General v Guardian Newspapers Ltd (No 2),* Lord Keith stated:[30]

> [I]t is in the public interest that confidences should be respected, and the encouragement of such respect may in itself constitute a sufficient ground for recognising and enforcing the obligation of confidence even where the confider can point to no specific detriment to himself.

Duty of confidence of doctors: doctor/patient relationship

As well as an ethical obligation, a doctor is under a legal obligation not to disclose confidential information learnt in the course of professional practice:[31]

> [I]n common with other professional men ... the doctor is under a duty not to disclose, without the consent of his patient, information which he, the doctor, has gained in his professional capacity, save ... in very exceptional circumstances.

An obligation to maintain confidentiality may be imposed by an express or implied contract. For example, it is an implied term of a contract between a doctor and patient that the doctor will maintain confidentiality as regards the patient's medical condition.[32] Yet Kennedy notes that little guidance is found in the law as to exactly when the contract between patient and doctor is formed, observing that contract may be more helpful to private patients than public ones.[33] *Tournier v National Provincial and Union Bank of England*[34] held that professional people such as lawyers, doctors and bankers owe obligations of confidence in terms of an implied contract. A plaintiff who has suffered actual physical harm may bring an action for negligent disclosure of confidential information, as was recognised in *Furniss v Fitchett.*[35]

Yet it is the very nature of the relationship itself that allows an equitable obligation of confidentiality to be implied. Equity has evolved a series of obligations, broadly described as obligations of good faith, which impose certain duties and standards of conduct on persons who occupy a position of trust or confidence

---

30 [1988] 3 WLR 776, 782 (HL).

31 *Hunter v Mann* [1974] QB 767, 772. A doctor was asked to give information under the Road Traffic Act 1972. He refused on the ground that the information was obtained solely through the relationship of doctor and patient.

32 Supra at note 22, at 13.

33 Kennedy & Grubb, *Medical Law: Text and Materials* (1989) 129.

34 [1924] 1 KB 461.

35 [1958] NZLR 396. The defendant doctor wrote a letter for the plaintiff's husband describing her as paranoid and deluded. The husband later used the letter in separation proceedings brought by the plaintiff. That was the first the plaintiff knew of its existence. She sued the defendant for breach of confidence.

in relation to others. In *McKaskell v Benseman* Jeffries J stated that:[36]

> ... the essence of the fiduciary relationship is one of trust and confidence governed by high ethical standards which equity mandates.

Barrowclough CJ observed that the doctor stands in a "special and peculiar fiduciary relationship" to the patient.[37] The doctor/patient relationship is clearly one which has trust and confidence at its foundation and, accordingly, it attracts the requisite high standard which that trust demands.

2. The Public Interest Factor

The universally endorsed constraints of the Hippocratic Oath are repeated in the International Code of Medical Ethics which was adopted by the World Medical Association in 1949.[38] That Code states that "a doctor owes his patient absolute secrecy on all which has been confided to him because of the confidence entrusted to him". However, the same Code also states that "a doctor must always maintain the highest professional conduct towards both the individual and *society*" (emphasis added). Unfortunately, no guidance is given in respect of the potential conflict between these two goals.

Potential conflict arises in determining what are "exceptional circumstances"[39] permitting disclosure. The British General Medical Council identified eight specific circumstances in which information may be disclosed. These include situations where information is shared with other health professionals participating in the patient's care, disclosure ordered by a court, and disclosure which is necessary for a medical research project approved by a recognised ethical committee.[40] Most of the exceptions leave a large degree of discretion in the hands of individual doctors. There is clearly a public interest factor in how this discretion is exercised.

Gurry suggests that the public interest has two principal roles in confidence issues:[41]

(i) It is in the public interest that information received in confidence is not used for other purposes. The public interest requires that confidences, like contracts, are inviolable.

(ii) The public interest has an opposing role which occasionally requires that confidences be broken.

In relation to the second role, the public interest requires that medical research continues to address problems which afflict society. When this research requires

---

36 [1989] 3 NZLR 75, 87.
37 Supra at note 35, at 404.
38 Supra at note 12, at 65.
39 Supra at note 31.
40 Supra at note 3, at 36.
41 Supra at note 24, at 325.

access to personal information without consent, the challenge is to find and maintain an acceptable balance between the need for access to information and the individual's right to privacy.

The Australian National Health and Medical Research Council ("NHMRC") states that privacy is not an intrinsic right; its value is instrumental. The NHMRC considers it proper to invoke privacy to prevent a person's financial standing being revealed to his detriment, but does not believe that privacy can be invoked to the extent that it inhibits the growth of knowledge about diseases, their causes and possible prevention. The NHMRC suggests that a parallel right, that is, a right to know, and to know the truth, should also be promoted and respected.

Yet this view may not be universally accepted. Privacy may be valued by many as a virtually intrinsic right. Rayner quotes Sir Zelman Cowan in his 1969 Boyer Lecture "The Private Man" as putting a high value on privacy, save in exceptional circumstances:[42]

> The claim to privacy protects an individual's solitude, his intimacy in various groups of his own choosing, his anonymity, his ability to be lost, without identification, in a crowd, his reserve, his shutting himself off from unwanted intrusion. To me this claim to privacy is clear beyond doubt; I see it as one of the truly profound values of a civilised society.

However, it is not clear as to exactly what the speaker may have considered to be "exceptional circumstances" or how he may have placed health benefits in relation to privacy in terms of value to society.

The public interest factor in balancing privacy with the need for information was further discussed by Knox, who expressed concern that existing access to medical records for research and other purposes is threatened by legal and bureaucratic measures imposed to protect confidentiality. Such measures are not necessarily guided by a technical knowledge of research needs, or a full appreciation of the dependence of improved health care on enquiries which utilise health records.[43] Knox also stated that the conflict is not between good and evil, but between two principles of equal merit. He suggested that the individual's right to privacy also needs to be qualified in order to protect the society which confers the right:[44]

> [N]either a concern for the individual nor a concern for mankind may hold absolute sway over the other.

The duty of confidentiality on the part of the doctor is not, then, absolute. There are a number of exceptions, some of which allow a considerable amount of discretion. Some, such as notification of certain infectious diseases, are given the sanction of the law.

---

42 Supra at note 22, at 12.

43 Knox, Editorial, "Confidentiality and the Use of Medical Records for Research" J R Coll Physicians Lond 1986; 20: 4, 224.

44 Ibid. Knox was referring to the conclusion of a group of research workers who met under the sponsorship of the European Economic Community to discuss issues of research and confidentiality.

The public interest factor in maintaining individual privacy, while allowing progress to be made toward the prevention of disease, is clear. Privacy, especially in terms of personal information imparted in a relationship of trust, is to be highly valued. Yet society and affected individuals bear the cost of disease. It is necessary that a reasonable approach be maintained in order to safeguard the privacy of patients adequately, without impeding the advancement of knowledge which can prevent disease.

3. Recent Australian Developments

The dilemma between individual privacy and the use of health records without individual consent may be illustrated by events in Australia in recent years. The Australian Law Reform Commission reviewed existing laws protecting privacy and made recommendations about possible new laws,[45] including the Privacy Bill which eventually led to the Privacy Act 1988. The Law Reform Commission regarded the public interest defence as the most controversial aspect of the law of confidence and advocated limiting its use to information relating to a misdeed of an offender, or where disclosure would avert an apprehended public injury.[46] The report stated:[47]

> Subject to the general rules authorising disclosure, a doctor cannot publish or otherwise disclose for research purposes any confidential information obtained about patients where the use or disclosure identifies or renders identifiable the patients in question.

The Commission acknowledged the existence of such disclosure in practice and considered it to be illegal.

It was apparent that a substantial amount of research, important to the health of the community, would be outlawed if the Commission's view prevailed.[48] Armstrong asserted that the Commission neglected the precedent provided by the long history of medical research based on health records. He cited the United States Privacy Protection Committee, which made a specific exception for "a biomedical or epidemiological research project" in respect of its general requirement for individual consent before access to health records is allowed.[49] Concern was also raised among hospital administrators that the Commission's view threatened the ordinary process of audit within hospitals and might interfere with medical education where students needed to examine case notes.

However the dilemma was slightly relieved by an intriguing piece of high-level intervention,[50] which resulted in the NHMRC being empowered to issue guide-

---

45 Supra at note 21.

46 Ibid, Vol 1, 395.

47 Ibid, 416.

48 Armstrong, "Privacy and Medical Research" Med J Aust (1984) 141, 620-621.

49 Ibid, 621.

50 Lovell, Chairman, Medical Research Ethics Committee, NHMRC, Address to Special Registries Workshop, Anti-Cancer Council of Victoria, 19 November 1987.

lines for the protection of privacy in the conduct of medical research. Under s 14 of the Privacy Act 1988, the only exceptions to the requirement of obtaining consent arise where disclosure:

(i) will prevent or lessen a serious and imminent threat to the life or health of the individual concerned or another person; or
(ii) is required or authorised under law; or
(iii) is necessary for enforcement of criminal law or to protect the public revenue; or
(iv) is directly related to the initial purpose for obtaining the information.

These exceptions do not cover the use of health records for medical research. Nevertheless, the provision under s 14 of the Privacy Act for the NHMRC to develop additional guidelines appears to be sufficient to allow medical research to continue in the absence of explicit consent. The guidelines may be approved by the Privacy Commissioner if "public interest" in medical research outweighs to a substantial degree the public interest in maintaining adherence to the Act.[51] This provision reflects the importance placed on medical research. With the proposed introduction of privacy legislation in New Zealand,[52] the Australian developments provide a useful background for analysis of the impact of any future legislation in this country.

IV: LEGAL ISSUES AND POSSIBLE REMEDIES

1. Existing Legal and Ethical Protection

Due to the lack of any specific privacy legislation in New Zealand, it is appropriate to examine those legal provisions which govern the transfer of personal health information to medical researchers in the absence of patient consent. In particular, the Hospitals Act 1957, the Area Health Boards Act 1983 and ethical guidelines will be reviewed.

(a) Hospitals Act 1957

In relation to hospital patients, s 139A(1) of the Hospitals Act states that:

> The Director-General of Health may from time to time request any licensee of a licensed hospital, and any medical practitioner who attends patients at a licensed hospital, to furnish medical information concerning the condition or treatment of patients *in the hospital in order to obtain statistics for medical purposes or for the purposes of advancing medical knowledge, education, or research.* [Emphasis added.]

[51] Privacy Act 1988, s 14.
[52] See text, infra at p20.

This provision operates in relation to patients in both public and private hospitals and would presumably extend to include day-stay patients, patients treated and discharged without admission (for example in accident and emergency clinics of public hospitals), and patients attending clinics as out-patients only.

It is important to note that the Act specifies that the Director-General of Health must request the furnishing of the information. It is possible to imply that, for this section to be effective at all, the researcher would need to request the information on behalf of the Director-General of Health.

(b) Area Health Boards Act 1983

Health records of patients in public hospitals administered by Area Health Boards are also made available to researchers pursuant to s 50 of the Area Health Boards Act. That section applies to:[53]

> Persons who are or have been employed by an area health board (whether in an honorary or a part-time capacity or otherwise, and whether as employees or independent contractors) ...

Furthermore:[54]

> Any person to whom this section applies may use or disclose any information concerning the condition or medical history of any patient for the purposes of the advancement of knowledge or research relating to any profession or activity associated with health services...

As well as allowing doctors in public hospitals to release patient information for appropriate research studies, this section is also useful in allowing medical researchers who are university employees to gain access to information by being appointed honorary employees of an area health board.

(c) Ethical guidelines

The position of the NZ Medical Association on the disclosure of patient information is clear:[55]

> A doctor shall keep in confidence information derived from a patient or from a colleague regarding a patient and divulge it only with the permission of the patient except where the law requires otherwise.

2. Implications for Current Research Projects

It is appropriate to apply the above criteria to existing research projects[56] in order to ascertain the adequacy of current legal safeguards.

Research projects utilising the Cancer Registry

In relation to projects utilising the Cancer Registry, the initial referral of private

---

53 Section 50(1)(a).
54 Section 50(5).
55 New Zealand Medical Association Code of Ethics (1989).
56 See text, supra at pp4-7.

patients was in a proportion of cases made by pathologists who did not routinely have any direct contact with surgical patients. Therefore, consent was unable to be obtained. As cancer is not a notifiable disease, there are no legal provisions which allow pathologists to provide patient information without consent.

In practical terms it was this situation which, however unfortunate, justifiably led to private pathologists discontinuing referrals to the Registry in 1985. At that time two women who had each had a breast tumour removed were approached for information by research groups who had obtained their names from the Cancer Registry. Neither woman had given permission for her name to be entered on a register, nor for it to be forwarded by the Registry to a research group. In both cases initial referral was made by a private pathologist.

Despite the fact that it would be preferable to collect information directly from pathologists, that is not possible in the present circumstances. Referral can only be made with patient consent. A similar problem arises with release of the patient's name and details from the Cancer Registry to a study group. This is compounded if the relevant study is carried out by a group in another city, and does not have approval of a local ethical committee. The present view of the New Zealand Cancer Society on this issue is that patients' names may not be liberated from the Cancer Registry without patient consent.

Current investigation into cardiovascular disease

In relation to the cardiovascular study referred to earlier,[57] there is no existing legislation authorising the disclosure of information, without individual patient consent, from general practitioners or private laboratories. Details pertaining to patients treated at home or in doctors' surgeries, and information contained in private laboratories, should not be obtained without individual patient consent.

3. Possible Remedies for the Patient

Having established that it is possible, although uncommon, for situations to arise where patient information is disclosed without adequate lawful authority, what possible remedies may a patient have against the doctor who disclosed the information, and against the third party using the information?

Current remedies

An action for breach of confidence could be based on the fiduciary nature of the doctor/patient relationship.[58] In *Duncan v Medical Practitioners Disciplinary Committee*[59] the matter of medical confidentiality was analysed. Jeffries J listed the exceptions to confidentiality, including where there is a legal requirement for

---

[57] Supra at note 17.

[58] See text, supra at pp9-10.

[59] [1986] 1 NZLR 513, 521.

disclosure. He stated that limited information may be made available to some outside agencies by a doctor from his or her files for statistical, accounting, data processing or other legitimate purposes.[60]

> The platform support of a description of medical confidence is to identify the doctor/patient relationship as a fiduciary one. Without trust it would not function properly so as to allow freedom for the patient to disclose all manner of confidences and secrets in the practical certainty they would repose with the doctor.

Although a "legitimate purpose" is not defined, the judgment suggests that the maintenance of confidentiality is paramount and, in the absence of patient consent, should be breached only in very unusual circumstances. This view is further strengthened when considered in the context of information disclosed in relation to illnesses which are not legally notifiable.

Equitable relief could provide an injunction preventing further disclosure of personal information. Although this remedy would only be helpful in an individual case if the doctor was continuing to disclose information on a follow-up basis, disease registers and epidemiological studies do require ongoing information about patients. If, in the case of a private patient, an action was brought for breach of contract, damages would be available. In the improbable, but not impossible, event that a person suffered physical harm from the disclosure, such as nervous shock with physical symptoms, a claim could be brought in negligence.[61] Concurrent liability is not ruled out, as may be seen from a recent case involving a successful action against an engineer in both contract and tort. It was held in that case that a contract did not negate tort liability.[62]

As regards remedies against the third party (being, in this instance, the researcher using the information), once the initial bond of confidence has been broken the information may become accessible to a wide range of people as a result of the confidant's indiscretions.[63] This possibility has lead the courts to restrain third parties by the issuing of an injunction. It is relevant to consider whether, at the time of receipt of the information, the third party has knowledge that the information was received in breach of confidence. This knowledge may be actual, imputed, or attributed by constructive notice[64] – although the circumstances in which the courts will apply the doctrine of constructive notice are uncertain.

Gurry suggests that the law relating to breach of confidence will be differentiated from the principles of constructive trusts as applied to strangers to a trust.[65] In

---

60 Ibid, 520.

61 Supra at note 35, at 402. Whether there is a duty is a question for the judge, but whether the duty has been breached is a question for the jury.

62 *Rowlands v Collow* [1992] 1 NZLR 178. The case also discussed *McLaren Maycroft & Co v Fletcher Development Co Ltd* [1973] 2 NZLR 100, which it said should be confined to its facts and held to be no longer authority against concurrent liability.

63 Supra at note 24, at 269.

64 Ibid, 270.

65 Ibid, 273.

the present situation, knowledge must be actual or, at the very least, imputed. Accordingly, any third party who acquires confidential information with the knowledge that the acquisition is facilitated by breach of confidence will be liable from the date of acquisition and may, in appropriate circumstances, be restrained by injunction.

Although the issue of an injunction may initially appear unlikely, a Commissioner of the Australian Law Reform Commission sought to warn medical researchers of that very risk.[66] Furthermore, as mentioned above, it was the possibility of legal action which caused private pathologists to cease referrals to the Cancer Registry in 1985, resulting in the subsequent difficulties with data collection. Thus, the possibility of a research project being interrupted due to the lack of legal safeguards for persons disclosing information is not entirely remote.

Possible developing remedies

A further possible remedy may lie in the developing tort of invasion of privacy. In *Tucker v News Media Ownership Ltd,*[67] McGechan J supported the introduction into the common law of a tort covering invasion of personal privacy, at least by the public disclosure of private facts. He quoted Jeffries J, stating in the same matter that:[68]

> The gist of the action, unlike defamation, is not injury to character or reputation, but to one's feelings and peace of mind.

A tort protecting privacy was also favoured by Holland J in *Morgan v Television New Zealand Ltd,* but he stated that it would need "some limitation where the public interest might well exceed that of the privacy of the individual".[69]

The existence of such a tort has yet to be considered by the Court of Appeal. Both the above cases concern news media publication, which is arguably more invasive than referral of personal information to a research group. However, due to the special nature of the doctor/patient relationship, it is not impossible that, if the tort were introduced, a court might view approaches made to a patient by a research group previously unknown to that patient as invasive of privacy. This would be all the more likely if the research group already possessed considerable personal information in respect of the patient. Nevertheless it is noteworthy that both Australia and the United Kingdom have rejected a general tort of invasion of privacy. It has been viewed as a threat to the legitimate circulation of information.

---

66 Hayes, "Epidemiological Research and Privacy Protection" Med J Aust 1984; 141: 621-624. It was stated that in many cases the subject might not be interested in damages. The remedy sought might be an injunction which could stop a very expensive research project in its tracks, in the absence of appropriate consent or legislative authority.

67 [1986] 2 NZLR 716, 733.

68 Ibid, 732.

69 High Court, Christchurch. 1 March 1990 CP 67/90 Holland J.

For the same reason, the United States has been reluctant to extend the tort of privacy into the field of personal information.[70]

Disciplinary proceedings

A doctor is under an ethical, as well as a legal, duty to maintain confidentiality:[71]

> There rests with a doctor a strong ethical obligation to observe strict confidentiality by holding inviolate the confidences and secrets he receives in the course of his professional ministerings.

Furthermore, although s 139A(3) of the Hospitals Act provides protection against civil and criminal liability, it is silent in relation to disciplinary proceedings.[72] The obligation to respect confidences is one of the most fundamental ethical obligations owed by a doctor to a patient. The New Zealand Medical Association recommends that doctors referring data relating to private patients do so with the consent of the patients. In the absence of any specified exceptions, disclosure of identifiable clinical information without the patient's consent would be regarded as serious professional misconduct. Therefore, if a complaint were laid under s 42A of the Medical Practitioners Act 1968, it could well be upheld by the Medical Practitioners Disciplinary Committee; this is in fact the most likely outcome for any breach of medical confidence.

Proprietary rights

A final remedy to consider is whether an action for breach of confidence protects a proprietary right to information, that is, whether the personal information contained in the health records is the actual property of the patient. If such information is regarded as property, this could result in an action for breach of confidence being based on a proprietary right in the information, rather than in equity or contract. The common law has traditionally refused to regard information as property,[73] although the case law is not consistent and some decisions have established a proprietary right in information. However, the majority of these cases involve information that is commercially valuable, in contrast to personal health information.[74]

In addition to the inconsistent case law, academic commentators are also in considerable disagreement as to whether a proprietary interest in confidential information can form the basis of an action for breach of confidence. Weinrib

---

70 Supra at note 21, at Vol 2, 25.

71 Supra at note 59.

72 Section 139A(3) provides that: "Notwithstanding any rule of law to the contrary, no licensee or medical practitioner shall incur civil or criminal liability by reason only that he furnished medical information in accordance with this section."

73 *Boardman v Phipps* [1967] 2 AC 46.

74 See for example *In re Keene* [1922] 2 Ch 475.

argues that if a court gives relief for unauthorised disclosure of information, it is in effect recognising an exclusive interest that should be protected, irrespective of any relationship between the parties.[75] Ricketson agrees that information, although intangible, is property. He suggests that a desirable basis for the action of breach of confidence lies in the adoption of a proprietary analysis.[76] However, Stuckey disagrees, arguing that breach of confidence arises out of a relationship of trust or confidence and neither protects nor acknowledges property rights in information.[77]

Given the continuing debate in relation to property in information, it is interesting to refer to the New Zealand Medical Association guidelines. They state that the information which a patient gives to a doctor remains the property of the patient, who may authorise the doctor to share the information with anyone the patient wishes.[78] It is uncertain, however, whether this would be upheld in a court.

At the present time, therefore, it seems impossible to state with certainty whether personal information contained in health records is the property of the patient to whom it pertains. The concept of information as property could provide a valuable extension to the breach of confidence action. Equity could be confined to circumstances where there is a relationship of confidence between a confider and a confidant, as well as a proven breach of the relationship through the passing of information to a third party.[79] As confidentiality between doctor and patient is protected by the fiduciary nature of the relationship, the question of a proprietary right in information, although of considerable interest, is not a prerequisite for the awarding of relief to a patient for the unauthorised disclosure of personal information to a third party.

V: PROTECTION OF PARTIES

There is a need for continued medical research, involving the use of personal health information, in order to establish causes of disease and preventive strategies. This requires the continuation of efforts to ensure the protection of all parties involved – patients, doctors and researchers. The public interest in the prevention and treatment of disease must also be taken into account. Several specific factors may help ensure this protection.

1. Recommendations as to Legislative Protection

Appropriate legislation may assist in ensuring the protection of all parties by:

---

75 Weinrib, "Information and Property" (1988) 38 University of Toronto LJ 117, 136.

76 Ricketson, "Confidential Information – A New Proprietary Interest?" Part II (1978) 11 Melbourne University LR 289, 314.

77 Stuckey, "The Equitable Action for Breach of Confidence: Is Information Ever Property?" (1981) 9 Sydney LR 402.

78 Ethical guidelines set out by the New Zealand Medical Association.

79 Supra at note 24, at 53.

(i) providing adequate privacy protection; and
(ii) making certain diseases legally notifiable.

The lack of adequate legislation for the protection of privacy in New Zealand remains a problem. The provisions of the Privacy of Information Bill relating to the appointment of a Privacy Commissioner have been removed and enacted in a separate piece of legislation, the Privacy Commissioner Act 1991.[80] The remainder of the Bill has been deferred by the Justice and Law Reform Select Committee. It is the task of the newly appointed Privacy Commissioner to analyse the principal submissions and to eventually report back to the Select Committee.

(a) Review of Privacy of Information Bill 1991

In contrast to the English Data Protection Act 1984, which provided only for electronically stored data, the Privacy of Information Bill ("the Bill") in its present form provides for electronically and manually stored data, thus covering all health records. Although it does not contain a specific exemption for medical information, the Bill appears to have avoided some of the more stringent provisions of the Australian legislation.

It is useful to consider the principles contained in the Bill as they apply to personal information.[81] The Bill provides that information can be collected directly from the individual concerned, with the knowledge and consent of the individual. However, the Bill provides for a number of exceptions, including where "non-compliance is required or authorised by or under law".[82] Similarly, the Bill contains an exception to the general principle that any information collected for a particular purpose shall not be used for any other purpose. The exception pertains to any use required or authorised by law, as well as use for statistical or research purposes which would not lead to publication in a form that could reasonably be expected to identify the individual concerned.[83]

Should the Bill be enacted in its present form, it would not directly affect disclosure of information relating to hospital patients, since such situations are already covered by existing legislation. However, it would cover situations such as general practice which are not protected by existing legislation.

(b) Compulsory notification of diseases

The practice of making certain diseases legally notifiable requires an assessment of exactly which diseases warrant being placed in this category. Tradition-

---

80 See Legislation Note, infra at p207.

81 Clause 2 defines personal information as "information about an identifiable individual". The Bill operates, inter alia, in relation to personal information collated by an agency, including any organisation or person in the public or private sector.

82 Clause 8, Principle 2(2)(e).

83 Clause 8, Principle 13(d) and (f)(ii).

ally, this protection has been reserved for certain contagious diseases where the public health need is paramount. In the case of cancer, there is no legislation in New Zealand which specifically empowers cancer registration. However this situation may soon be remedied by the very recent introduction of the Cancer Registry Bill, a private member's Bill modelled on existing Australian legislation.[84] The Bill provides, inter alia, that the person in charge of any place where a cancer test is undertaken shall report that test to the Director-General of Health.[85] Clause 5 provides for protection of persons making the report from any civil or criminal liability, while clause 6 imposes an obligation of secrecy on persons receiving the information, with a very limited number of exceptions.

Such legislation would remove any ambiguities as to the legal position of doctors and would itself enhance the likelihood of adequate safeguards to protect patient confidentiality. An alternative view, less acceptable to medical researchers, is that the legal mechanism to register the majority of cancers is already in place, given the existing statutory provisions allowing referrals from both public and private hospitals. Referrals from private pathologists in the past merely provided an easy and inexpensive method of registration.[86]

On this view further legislation may be unnecessary and may represent an unwarranted intrusion into patient confidentiality and autonomy. In addition, the introduction of individual pieces of legislation, while commendable in terms of the particular disease identified, fails to address the wider issues of the number and nature of diseases which should be subject to compulsory registration. The duty of confidentiality is circumvented on a somewhat random basis, with a corresponding increase in the amount of information held in various places.

(c) Benefits of ethical guidelines

Appropriate guidelines for research projects are particularly important in ensuring the continued protection of private and public interests. Guidelines are available from two sources:

(i) the ethical committees of Medical Research Councils and Medical Associations; and
(ii) within individual studies themselves.

The purpose of guidelines is to set out the principles and standard of practice

---

[84] For example, in Victoria the Cancer Act 1981 provides for compulsory notification from public and private hospitals and pathologists, but there is no legal obligation to provide follow-up data. It is anticipated that the New Zealand Bill will be considered by the Select Committee in the last quarter of 1992.

[85] Clause 4.

[86] If a disease is legally registrable, a fee is charged by the registering doctor.

expected in relation to research work based on personal health information. With all guidelines, the overruling consideration must always be that no harm or distress will accrue to the individual or his or her family, and that the doctor/patient relationship will in no way be impaired. Guidelines also emphasise the responsibilities of all parties, including those of the referring doctor, in order to ensure the security of all information:[87]

> A doctor has a duty to examine record storage systems and if he is not satisfied with the security and confidentiality of his patients' records, he should refuse to place clinical information in them.

(d) Health Commissioner Bill 1990

The Health Commissioner Bill, yet to be enacted, resulted directly from recommendations contained in the Cartwright Report into cervical cancer.[88] The Bill provides for the appointment of a Health Commissioner who will investigate complaints against persons or bodies that provide health care. The Commissioner will also have general functions relating to the protection of the rights of health consumers. This Bill has the potential to preserve and strengthen the confidentiality of health records. Any person receiving health care is protected, and the wider definition of health care provider ensures that protection occurs not only in relation to hospital treatment but in all areas of health care.[89]

Clause 13 sets out the functions of the Health Commissioner, whose first priority will be to prepare a Code of Health Consumers' Rights. Certain provisions must be contained in that Code, including:[90]

> The rights of health consumers, and the duties and obligations of health care providers, as they relate to –
> (i) Matters of privacy and the confidentiality of health consumer information:
> (ii) Health teaching and health research that involve the participation of health consumers:
> (iii) The collection and use of information from health consumers for administrative or epidemiological purposes ...

Remedies available to the Commissioner include civil proceedings before the Equal Opportunities Tribunal. If a breach is established, the Tribunal can make an order:[91]

> ... restraining the defendant from continuing or repeating the breach, or from engaging in, or causing or permitting others to engage in, conduct of the same kind as that constituting the breach, or conduct of any similar kind specified in the order ...

---

87 British Medical Association, *Handbook of Medical Ethics* (1980) 15. These guidelines have been endorsed by the Medical Research Council of New Zealand: see the Medical Research Council of New Zealand, *Project and Programme Grants* (1986).

88 *The Report of the Committee of Inquiry into Allegations Concerning the Treatment of Cervical Cancer at National Women's Hospital* (1988) (Cartwright Report).

89 Clauses 3 and 4.

90 Clause 17(3)(c).

91 Clause 41(1)(b).

In addition, clause 54 provides that medical records shall not be made available without the health consumer's consent, except where that is specifically provided for by the Hospitals Act and the Area Health Boards Act.[92]

These provisions clearly give added protection to the confidentiality of personal health records. The code specifically protects health consumer information, including the use of this information for reasons other than its original purpose.

(e) The Health Research Council Act 1990

This Act has the potential to impact indirectly on issues of confidentiality of personal health information, if only because it will assist to increase the amount of public health research, including epidemiology, undertaken. Any increase in the volume of research performed will result in an increase in the use of personal health information. This gives practical weight to Kennedy's suggestion that issues of confidentiality of information will become increasingly important.[93]

The Act provides for the establishment of an Ethics Committee[94] which will have an important contribution to make in terms of balancing rights to privacy of confidential information with the needs of society for useful research.

(f) New Zealand Bill of Rights Act 1990

The New Zealand Bill of Rights Act 1990 is an Act to affirm, protect, and promote human rights and fundamental freedoms. It does not, however, address any specific right to privacy, nor does it appear to have any impact on rights to confidentiality of personal health information. Section 28 states that a right or freedom is not abrogated or restricted by reason only that it is not included (or is included only in part) in the Bill of Rights. Section 10 provides that every person has the right not to be subjected to medical or scientific experimentation without personal consent. However, this provision does not extend to the use of personal information for research purposes.

The only possible protection that the Act may offer would arise in a situation where personal information was regarded as property. Section 21 provides a right not to be subjected to unreasonable search or seizure of person, property, correspondence or otherwise. If it is established that personal information is property, this provision may be helpful in the event of health records being used by a study which does not comply with the statutory or ethical guidelines. Since s 4 states that other enactments are not affected, the Bill of Rights would not override the provisions of the Hospitals Act or the Area Health Boards Act.

---

92 It is anticipated that these statutes will be repealed by the proposed health reforms legislation which is currently scheduled to be enacted in the first quarter of 1993. As the proposed health reforms are implemented, new issues will be raised concerning the exchange of patient information, and the maintenance of confidentiality, between separate providers of health services.

93 See supra at note 4 and accompanying text.

94 Section 24.

2. Role of Ethics Committees

Although ethical and legal issues may be separated, ethical committees play an important role in the protection of confidentiality. Given that ethical committees are influential in deciding which particular studies have access to information, their responsibility is significant.

However, an individual doctor's duty regarding disclosure of patient information is still subject to legal constraints and to the ethical guidelines of his or her professional association.[95] An ethical committee cannot legitimise the disclosure of information without consent in situations where it is not specifically allowed by the law.

Despite the fact that a research study has been approved by an ethical committee, any doctor disclosing information to that study outside statutory guidelines could be vulnerable to an action for breach of confidence and/or to disciplinary proceedings. Hayes states:[96]

> One danger of guidelines, peer review, ethics committees, and other extra legal mechanisms for securing professional accountability is that they might, whether through ignorance or blindness born of their own professionalism, endorse practices which, in fact, might depart from the requirements of the substantive law.

Hayes further comments that privacy may be forgotten when a project is suffused with the aura of public interest. It is important in this regard to recognise that there is no authority for a general practitioner or any doctor in private practice to disclose information without patient consent except where it is required or allowed by the law.

The purpose of ethics committees is to ensure that research takes place under proper ethical constraints: to promote the ethical and to prevent the dubious.[97] The relationship of trust between patient and doctor must not be abused. The appropriate composition of ethical committees is especially important to the attainment of this objective. It is necessary to maintain sufficient members with expertise to ensure the scientific validity of studies, but also to include members with other valuable perspectives.

Because ethical approval does not in fact guarantee that a study meets all legal requirements, advice from appropriate professional organisations is a further way of protecting all parties involved.

---

95 Supra at note 55.

96 Supra at note 66, at 623.

97 Ethics Working Party, Auckland Area Health Board, *Draft Proposal on the Formation of Ethics Committees* (1989).

VI: CONCLUSION AND RECOMMENDATIONS

The valuable contribution made by medical research through the utilisation of personal health records is indisputable. Individuals as well as society have benefited, and will continue to benefit, from these types of studies. At a time when many apparently urgent health priorities compete for increasingly inadequate resources, efforts towards prevention of disease assume renewed importance. However, there is a trade-off in that information is collected, stored, and used without the individual patient's consent and usually without the patient's knowledge.

However, even such an altruistic motive as prevention of disease is not sufficient reason to impinge upon basic human rights. The challenge, then, is to maintain a balance between the right to privacy, which is protected by the duty of confidentiality, and the rights and duties of society regarding the prevention of illness. It is necessary to determine what, if any, are reasonable restrictions on the use of personal information in order to protect privacy interests.

The most appropriate way of achieving this balance is by further defining the parameters of privacy and by determining what information pertaining to health should be notifiable at any given time. With regard to privacy, *Tucker v News Media Ownership Ltd*[98] has already recognised that there may be a right of privacy in relation to personal information. It is appropriate that Parliament, rather than the courts, address this issue.

The second way to achieve balance is to consider the notifiability or otherwise of specific diseases. The value and desirability of any strategy to improve the prevention and treatment of cancer or heart disease is undeniable. It is true that many patients are happy to share something in the hope that others may benefit. When considering statutory registration of any disease, the paramount factor must be the balancing of the necessity for compulsory registration against the possibility of achieving a satisfactory result through imposing a requirement to obtain patient consent. The latter possibility has the advantage of not impinging on patient confidentiality. It is possible, however, that while people may accept their name being placed on a cancer register, there could be considerably more resistance to names being placed on a register for schizophrenics, AIDS-related illnesses, or other less socially acceptable diseases.

There is an urgent need for legislation to protect privacy of information. Legislation compelling disclosure should be express, rather than simply subjecting doctors to a general requirement to disclose information. Accompanying this, there needs to be a review of medical confidentiality in relation to compulsory disclosure, and clarification as to exactly when the public interest should override rights to confidentiality. The appointment of a Privacy Commissioner is welcome. The Commissioner will play an important role in implementing recommendations and

[98] Supra at note 67.

guidelines regarding the dissemination of personal health information for reasons other than the original purpose.

Ultimately, the balance between privacy and the public interest in research access to personal health information is determined by policy, as reflected through the courts and Parliament. Policy decisions also determine the direction that health takes; in the newly restructured and competitive health environment in New Zealand, issues of confidentiality and exchange of information will be of even greater importance. Increasingly, the law will be required to take a pivotal role in these decisions, striving always to maintain a balance between the needs of society and individual rights.