

# **ACCESS TO MEDICAL RECORDS**

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**KAREN SAMPFORD**

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## ABSTRACT

*In Australia, in the public health sector, consumers have a right of access to their medical records under Freedom of Information legislation (with the exception of the Northern Territory). However, Commonwealth and State Freedom of Information provisions do not apply to private hospital records or the records private medical practitioners keep about their patients. In NSW, regulations give patients in private hospitals, nursing homes and day procedures centres the right to access their personal medical records, and in the Australian Capital Territory, the Health Records (Privacy and Access) Act 1997 now provides individuals with a generic right of access to records held by health service providers in the Territory. However, legislative reform has yet to be extended into the private health sector nation-wide, despite various calls for reform. The dichotomy between the private and public health care sectors has been highlighted most recently in the 1996 High Court decision in Breen v Williams which confirmed the absence of a common law right to access to medical records.*

*This Research Bulletin examines and compares the public and private sector position on access to medical records (Sections 2 and 3), and looks at calls made for legislative reform of the private sector (Section 5) to override the common law principles laid down in Breen v Williams (discussed in detail in Section 4). The provisions of the Australian Capital Territory's Health Records (Privacy and Access) Act 1997 are outlined in Section 6 of the Bulletin, while statute and case law decisions allowing access to medical records in various overseas jurisdictions are discussed in Section 7. Some limited evidence on the frequency with which access to medical records is sought is described in Section 8, and the reasons why people seek access are explored in Section 9. In section 10, arguments for, and against, allowing individuals access to their own personal health records are canvassed.*



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## 1. INTRODUCTION

In Australia, in the public health sector, consumers have a right of access to their medical records under Freedom of Information legislation and, to a lesser extent, in accordance with government departmental policies and guidelines<sup>1</sup> (although this does not mean that they own the records). In the private sector, consumers have a right to results of medical tests, x-rays and similar reports for which they have paid,<sup>2</sup> but they do not have a general right of access to the records kept by medical practitioners, hospitals and other health professionals, as was highlighted most recently in the 1996 High Court decision in *Breen v Williams*. This dichotomy between the private and public health care sectors has led to calls for legislative reform, which to date has taken place only in the Australian Capital Territory where the *Health Records (Privacy and Access) Act* was passed in 1997. The Act, which came into effect on 1 February 1998,<sup>3</sup> now provides individuals with a generic right of access to private sector medical records.

This *Research Bulletin* examines and compares the public and private sector position on access to medical records (Sections 2 and 3), and looks at calls made for legislative reform of the private sector (Section 5) to override the common law principles laid down in *Breen v Williams* (discussed in detail in Section 4). The provisions of the Australian Capital Territory's *Health Records (Privacy and Access) Act 1997* are outlined in Section 6 of the Bulletin, while statute and case law decisions allowing access to medical records in various overseas jurisdictions are discussed in Section 7. Some limited evidence on the frequency with which access to medical records is sought is described in Section 8, and the reasons why people seek access are explored in Section 9. Section 10 looks at arguments for and against allowing individuals access to their own personal health records.

## 2. ACCESS TO MEDICAL RECORDS IN THE PUBLIC SECTOR

All Australian jurisdictions, except the Northern Territory, allow individuals access to their personal medical records held by governmental bodies and authorities under freedom of information legislation. Access may nonetheless be refused if the information, if disclosed, would have an adverse effect on the physical or mental

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<sup>1</sup> Public Interest Advocacy Centre (PIAC), *Whose Health Records?: Attitudes to Consumer Access to their Health Records and the Need for Law Reform*, October 1996, pp 13-14.

<sup>2</sup> *Breen v Williams* (1996) 138 ALR 259 (High Court of Australia) per Dawson and Toohey JJ at p 270.

<sup>3</sup> 'Access to medical records - landmark legislation', *Alternative Law Journal*, 23(1), February 1998, pp 35-36, at p 35.

health of the applicant. However, even in such cases, provision is made under the freedom of information legislation for access to be given to a registered medical practitioner nominated by the applicant.<sup>4</sup>

### 3. ACCESS TO MEDICAL RECORDS IN THE PRIVATE SECTOR

As explained in Section 2, freedom of information legislation permits access to medical records but this applies only to records held in government health facilities. In New South Wales, the Private Hospitals,<sup>5</sup> Day Procedures Centres,<sup>6</sup> and Nursing Homes Regulations 1996<sup>7</sup> also give patients treated in those facilities similar rights to access their records as are available in public health services under FOI legislation. However, according to the Public Interest Advocacy Centre, which sought to canvass consumer opinion on key issues related to providing individuals with access to their personal health records:

*The practical use of the rights have been fairly limited, due to a lack of awareness of the rights by hospital staff and consumers. A number of submissions reported incidents of nursing home and private hospital staff providing consumers with misleading or incorrect information about their rights. The NSW Privacy Committee reported a hospital that had wrongly told a consumer they needed to justify a request for the records. Another common claim is that the regulations provide only a right to see the records, not to copy them. This effectively prevents people seeking independent advice in interpreting them. New regulations ... have clarified this issue...*<sup>8</sup>

The current regulations<sup>9</sup> (cited above) provide separate rights, upon written application, to inspect records, or to receive a copy of the records or specific parts thereof, or to have records explained.<sup>10</sup>

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<sup>4</sup> *Freedom of Information Act 1982* (Cth), s 41(3); *Freedom of Information Act 1992* (Qld), s 44(3); *Freedom of Information Act 1989* (NSW), s 31(4); *Freedom of Information Act 1982* (Vic), s 33(4); *Freedom of Information Act 1991* (SA), s 26(4); *Freedom of Information Act 1992* (WA), s 28; *Freedom of Information Act 1991* (Tas), s 30(7); *Freedom of Information Act 1989* (ACT), s 41(3.)

<sup>5</sup> The Private Hospitals Regulation 1996 is made pursuant to the *Private Hospitals and Day Procedure Centres Act 1988* (NSW).

<sup>6</sup> The Day Procedure Centres Regulation 1996 is made under the *Private Hospitals and Day Procedure Centres Act 1988* (NSW).

<sup>7</sup> The Nursing Homes Regulation 1996 is made under the *Nursing Homes Act 1988* (NSW).

<sup>8</sup> PIAC, *Whose Health Records?*, p 13.

<sup>9</sup> The 1996 regulations replace 1990 regulations of the same name.



Health complaints commissions in various Australian jurisdictions cover the private as well as public health sector and usually operate under statutory guidelines which encourage access to health records.<sup>11</sup> For example, in Western Australia, the *Health Services (Conciliation and Review) Act 1995* includes, as a principle for the guidance of health services providers, that health services should be provided so as to promote reasonable access to information in records relating to personal use of the health care system, except for information that is expressly prohibited by law from being disclosed or information contained in a health care provider's personal notes: s 4(1)(f). In Victoria, under the *Health Services (Conciliation and Review) Act 1987*, a health care user or his or her representative may make a complaint to the Health Services Commissioner if a health care provider has acted unreasonably by denying or restricting the user's access to records kept by the provider and which relate to the user: s 16.

In the absence of provisions such as those outlined above, common law principles, outlined in Section 4, will apply to individuals seeking access to their medical records in the private health sector.

#### 4. THE COMMON LAW POSITION

At common law, a patient's records are considered to belong to the health care professional or establishment, as the primary reason for the creation of the record is to assist the health care provider.<sup>12</sup> Although a patient owns the factual information which makes up his or her medical history, where the doctor applies professional knowledge or opinion to the patient history to document the results of a consultation, the medical record becomes the property of the physician or the health care establishment.<sup>13</sup> While continuing to accept the notion that ownership of medical records rests with the relevant physician or health care establishment, developments in Canadian and United States case law have held that a physician has a fiducial duty (ie a duty arising from the special relationship of trust and confidence that exists between a physician and a patient) to make proper disclosure of information to the patient (see Sections 7.3 and 7.4). This doctrine has not,

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<sup>10</sup> PIAC, *Whose Health Records?*, p 13 and see for example, ss 42-44 of the Private Hospitals Regulation 1996 (NSW).

<sup>11</sup> PIAC, *Whose Health Records?*, p 13.

<sup>12</sup> Review of Professional Indemnity Arrangements for Health Care Professionals (PIR), *Compensation and Professional Indemnity in Health Care: An Interim Report*, AGPS, Canberra, February 1994, pp 158-59.

<sup>13</sup> *Halsbury's Laws of Australia*, "Ownership of patient records", para 280-4010; *Breen v Williams* (High Court) per Brennan CJ at p 264.

however, yet been accepted in Australian case law. In Australia, the most recent test case on access to medical records at common law took place in *Breen v Williams*.

In *Breen v Williams* (1996) 138 ALR 259, on appeal from the New South Wales Court of Appeal, the High Court dismissed the claim that patients have a right of access at common law to the medical records compiled about them by their doctors.

#### 4.1 THE FACTS IN BREEN V WILLIAMS<sup>14</sup>

In October 1977, Ms Julie Breen (the plaintiff/appellant) underwent a bilateral augmentation mammoplasty (implant breast enlargement) performed by Dr Sharp. After the operation, Ms Breen developed symptoms of hardening around the silicon implants, for which she consulted Dr Williams (the defendant/respondent). In November 1978 he carried out an operative procedure in which the fibrous capsule around the implants was broken down. Subsequently, Ms Breen wrote to Dr Williams asking for advice about the removal of the implants and other unrelated plastic surgery, but no further consultations took place. In 1984, Ms Breen developed a lump under her left breast which was diagnosed by Dr McDougall as a leakage of silicon gel from the implant. As a result, Ms Breen underwent a partial mastectomy to treat the rupture and leakage of her implants.

In 1993, Ms Breen became involved in a class action against the manufacturer of the breast implants (Dow Corning Corporation), contending that the implants were defective.<sup>15</sup> In August 1993, as part of a “test” case to ascertain whether a legal right to medical records could be established, independently of a court order that the records be produced, Ms Breen’s solicitors wrote to Dr Williams, requesting copies of all her primary records and emphasising that it was not a medical summary that was sought.

Dr Williams replied directly to Ms Breen, stating that it was a “*longstanding legal tradition*” that such records were the “*property*” of the doctor, constituting “*an aide memoire to his treatment of the patient*” which could only be released upon production of a court subpoena.<sup>16</sup> Ms Breen subsequently proceeded by summons heard before Bryson J in May 1994. During the hearing, Dr Williams made an open

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<sup>14</sup> The outline of the facts in the case is drawn from Kirby P’s judgment in *Breen v Williams* (1994) 35 NSWLR 522 (NSW Court of Appeal) and Dawson and Toohey’s joint judgment in the High Court case.

<sup>15</sup> At least 2000 Australian women were engaged in the litigation, which was begun in a United States Court.

<sup>16</sup> as quoted in *Breen v Williams* (NSW Court of Appeal) at p 528.

offer to provide a report to Ms Breen, but the offer was not then accepted. That report, of less than two pages, was subsequently produced to the New South Wales Court of Appeal at the close of its hearing. Kirby P commented that the report “... *certainly does not meet Ms Breen’s asserted ‘right’ to ‘... have all information relating to my personal health at my disposal which will, in turn, ensure that I am able to make decisions regarding my future treatment’*”.<sup>17</sup>

In his decision, Bryson J held that medical records were the property of a physician and upheld Dr William’s right to control access to them:

*It is his legal right to keep them to himself, keep them secret or to show them to anyone he chooses and to impose conditions such as furnishing releases or indemnities or paying fees, if he is to allow anyone to see them.*<sup>18</sup>

## 4.2 BEFORE THE NSW COURT OF APPEAL

The New South Wales Court of Appeal, by a majority, dismissed Ms Breen’s appeal. In its judgment the Court held, inter alia, that the relationship between doctor and patient was not of such a fiduciary nature as to provide a patient with a right to inspect the doctor’s notes and records about the patient<sup>19</sup> (although Kirby P, dissenting, took the view that the matter was one of fiduciary duty). Commenting after the decision handed down by the NSW Court of Appeal, Scott, writing in the *Queensland Law Society Journal* in August 1995, stated:

*It can be argued that the Courts hearing Breen v Williams failed to take proper and adequate judicial notice of a number of public policy issues and facts. For example, it is difficult to reconcile a dichotomy on the issue of patient access to medical records, between the public and private health sectors. This is particularly poignant in Queensland where even full-time employees of Regional Health Authorities may have a right to private practice entitling those doctors to admit patients to ‘intermediate’ beds in state public hospitals and even private beds in private hospitals remote from the public hospital at which they are employed.*<sup>20</sup>

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<sup>17</sup> *Breen v Williams* (NSW Court of Appeal) per Kirby P at p 528.

<sup>18</sup> quoted in ‘Patient appeals for record access’, *Australian Medicine*, 6(20), 7 November 1994, p 4.

<sup>19</sup> *Breen v Williams* (NSW Court of Appeal) at 568E, 570E.

<sup>20</sup> Russ Scott, ‘*Breen v Williams* and Patient Access to Medical Records’, *Queensland Law Society Journal*, August 1995, pp 315-327 at p 325.

### 4.3 BEFORE THE HIGH COURT

On appeal to the High Court, a bench of six judges (comprised of Brennan CJ, and Dawson, Toohey, Gaudron, McHugh and Gummow JJ<sup>21</sup>), unanimously decided that Ms Breen did not have a right of access to the information contained in the medical records created by Dr Williams. Ms Breen had variously contended that the nature of her right to access resided in:

- a patient's proprietary right or interest in the information contained in the medical records
- an implied term of the contract between doctor and patient
- a fiduciary relationship between doctor and patient,

however, all these claims were rejected. In addition, in furtherance of the above claims, rather than as an independent ground of claim, Ms Breen submitted that there was a movement in the law governing the relationship between doctor and patient in the direction of the principle of personal inviolability and patient autonomy and the rejection of medical paternalism. For this purpose the plaintiff sought to rely upon *Rogers v Whitaker* (1992) 109 ALR 625. In this case, the High Court held that doctors may be guilty of medical negligence for failing to warn patients of material risks inherent in their proposed treatment. Whether the patient has been given all the relevant information to choose between undergoing and not undergoing treatment, said the Court, does not depend upon the standards and practice adopted by the medical profession, but is rather a question to be decided by the court. However, this claim was also rejected (Dawson, Toohey, Gaudron and McHugh JJ, with Brennan CJ concurring).

Ultimately, the court pointed out, if any change in the law was to be effected, this would be a matter for Parliament. Thus, in their joint judgment, Gaudron and McHugh JJ stated that:

*... No doubt there are people in this country who think that a patient should have an unrestricted right of access to medical records that concern that patient. Many others ... no doubt think that a patient should have access to such records, subject to limited exceptions. Perhaps only a very small minority of persons in Australia would think that in no circumstances should patients have access to information contained in their medical records. But absent a contractual right, the common law of Australia does not give a patient a right to have access to records, compiled by a medical practitioner, which relate to that patient.*

*... In a democratic society, changes in the law that cannot logically or analogically be related to existing common law rules and principles are the*

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<sup>21</sup> By the time the case reached the High Court, Kirby J had been appointed to the Court. As he had been President of the New South Wales Court of Appeal from which the appeal came, he did not sit to hear the High Court case.

*province of the legislature. From time to time it is necessary for the common law courts to reformulate existing legal rules and principles to take account of changing social conditions. Less frequently, the courts may even reject the continuing operation of an established rule or principle. But such steps can be taken only when it can be seen that the 'new' rule or principle that has been created has been derived logically or analogically from other legal principles, rules and institutions.*

*In the present case, it is not possible, without distorting the basis of accepted legal principles, for this court to create an unrestricted right of access to medical records or a right of access, subject to exceptions. If change is to be made, it must be made by the legislature.<sup>22</sup>*

In a similar vein, Dawson and Toohey JJ in the conclusion to their judgment, said that, as the desirability of the views advanced by Ms Breen were far from self-evident, and there was more than one view upon the matter, the choice was appropriately for the legislature rather than the court.<sup>23</sup>

## **5. PUBLIC INQUIRIES**

A number of key public inquiries have called for law reform in the area of access to medical records. Findings from key inquiries are discussed below.

### **5.1 REVIEW OF PROFESSIONAL INDEMNITY ARRANGEMENTS FOR HEALTH CARE PROFESSIONALS**

In its Interim Report, published in February 1994, the Review of Professional Indemnity Arrangements for Health Care Professionals (the PIR) noted that:

*One topic of considerable concern to consumers is the difficulty in accessing their own medical records. While it is apparent that access to medical records would be necessary in the conduct of litigation, the need for access has, in fact, been identified as a potential cause of litigation. Either the patient has to commence litigation to obtain access to her or his record through a subpoena, or the patient sees a denial of access to the record as a sign of a "cover up". This latter concern was an issue for several participants in the PIR's Case Study Report, where they experienced difficulty trying to obtain their medical records. Despite preferring to maintain a good relationship with the health care professional, persistent problems with obtaining information damaged the trust which patients had in their health/medical provider(s) and paved the way for future confrontation. In many instances, consumers who have suffered an adverse*

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<sup>22</sup> *Breen v Williams* (High Court) at pp 290-91.

<sup>23</sup> per Dawson and Toohey JJ at p 278.

*outcome are unable to access medical records except by way of litigation. In consultations, this issue was drawn frequently to the PIR's attention by both consumers and lawyers.*<sup>24</sup>

Noting that the two main methods of improving patients' access to their medical records were through legislative changes, or via codes of conduct, the PIR recommended that the option of improving patients' access to their records via legislative changes be explored in its Final Report. In the interim, the PIR undertook to consult with the Australian Medical Association, medical defence organisations, other health care professionals and consumers to determine whether agreed upon codes of conduct could be used to improve access in the short-term. If codes of conduct were to be agreed upon, consideration would need to be given to whether legislative action was required after all.

As regards health care establishments, the PIR recommended that patients' access to their medical records in all health care establishments be facilitated either through the enactment of legislation or the implementation of protocols or guidelines.<sup>25</sup>

In its Final Report, released in November 1995, the PIR recommended that, if necessary, following the outcome of *Breen v Williams*, the Commonwealth should ensure that patients have a statutory right of access to their own health care records held by doctors, other health care professionals and public and private health care facilities. The PIR believed that the minimum requirement should be right of access to all records created **after** such legislation commenced and access to matters of fact, including test results, for records created **before** the legislation commenced.<sup>26</sup>

However, in the interim, guidelines issued in March 1994 by the Federal Council of the Australian Medical Association took the view that:

- access to medical records should be a matter for negotiation between patients and their doctors
- the doctor's opinions and conclusions contained in the medical record should be released only at the discretion of the doctor concerned
- if patients' medical records are maintained by a hospital or other organisation, identical principles as for an individual doctor should apply to the release of information.<sup>27</sup>

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<sup>24</sup> PIR, *Interim Report*, p 158.

<sup>25</sup> PIR, *Interim Report*, p 161 (Recommendations 22 & 23).

<sup>26</sup> Review of Professional Indemnity Arrangements for Health Care Professionals (PIR), *Compensation and Professional Indemnity in Health Care: Final Report*, AGPS, Canberra, November 1995, Recommendation 44, at p xxii in The List of Recommendations.

<sup>27</sup> Australian Medical Association, 'Guidelines on Patients' Access to Records Concerning their Medical Treatment', March 1994, published in *Australian Medicine*, 6(20), 7 November 1994.

## 5.2 REPORT OF THE INQUIRY INTO THE USE OF PITUITARY DERIVED HORMONES IN AUSTRALIA AND CREUTZFELDT-JAKOB DISEASE

In June 1994, the Inquiry into the Use of Pituitary Derived Hormones in Australia and Creutzfeldt-Jakob Disease published its Report. The Inquiry was established in May 1993 following confirmation that four Australian women who were treated with pituitary derived hormones in the course of infertility treatment had died of Creutzfeldt-Jakob Disease (CJD). CJD is a rare disease belonging to a group of transmissible neurodegenerative diseases known as spongiform encephalopathies, and resulting in rapidly progressive dementia and death.<sup>28</sup> The women who had contracted the disease had received treatment under the Australian Human Pituitary Hormone Program (AHPHP) in which pituitary derived hormones were made available to treat infertility and growth hormone deficiency.

In the course of the inquiry, considerable attention was paid to difficulties experienced by former patients in accessing records.

The Inquiry found that fundamental difficulties had been encountered:

- in tracing patients treated with pituitary derived hormones under the AHPHP and treated unofficially, and
- by patients in attempting to gain access to their own records.

Furthermore, the Inquiry took the view that the spirit of the Commonwealth *Freedom of Information Act* had been undermined by an insistence that personal information held by the Department of Health be made available only through a medical practitioner. According to the Inquiry, this policy could not be supported by those provisions in the Cth *Freedom of Information Act* which provide for release, through the intermediary of a medical practitioner, of information about a person's mental state which might cause harm to the person.

Accordingly, the Inquiry recommended:

That the Commonwealth Department of Health initiate and coordinate the development of a uniform Federal/State approach to accessing and disposing of medical records, which would:

- apply to records held in public hospitals and also to records held by private doctors and private hospitals
- provide legally enforceable rights of patients with regard to access and disposal of records, either by extending freedom of information legislation in

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<sup>28</sup> *Report of the Inquiry into The Use of Pituitary Derived Hormones in Australia and Creutzfeldt-Jakob Disease* (CJD), AGPS, Canberra, June 1994, p 281; *Mosby's Medical, Nursing and Allied Health Dictionary*, 4<sup>th</sup> edn, 1994, and Peter Reilly, 'Creutzfeldt-Jakob disease: an update', *Modern Medicine of Australia*, February 1999, pp 100-104.

each jurisdiction or by applying conditions to providers under the Medicare scheme.<sup>29</sup>

### 5.3 REVIEW OF THE FEDERAL FREEDOM OF INFORMATION ACT 1982

In July 1994 the Australian Law Reform Commission (ALRC) and the Administrative Review Council (ARC) were asked to undertake a review of the Commonwealth's freedom of information legislation. During the course of the review, several submissions were received arguing for legislation to be enacted to enable patients to gain access to private sector health and medical records. The Review expressed the belief that access to medical and health records in the private sector could be dealt with as part of a comprehensive national privacy scheme.<sup>30</sup>

### 5.4 QUEENSLAND CODE OF HEALTH RIGHTS AND RESPONSIBILITIES

Under s 37 of the *Health Rights Commission Act 1991* (Qld), the Queensland Health Rights Commissioner was required to develop a Code of Health Rights and Responsibilities for the Minister's consideration, within three years after the commencement of the Act. Section 39 of the Health Rights Commission Act requires the Health Rights Commissioner to have regard to certain principles in developing the Code, including the principle that "*an individual should be entitled to reasonable access to records concerning the individual's health*".

In December 1994, the Queensland Health Commission released a draft Code and Discussion Paper. Prior to the draft Code's formulation, an *Invitation to Contribute to the Development of a Code of Health Rights and Responsibilities* (Phase 1) had been issued. Responses to this document provided the major substance and form for the development of the draft Code. In Phase 2, public consultation was invited on the draft Code and Discussion Paper. Following analysis of the issues raised in Phase 2, it was intended that the form of the Code would be finalised.<sup>31</sup> In its 1994 Discussion Paper, the Queensland Health Rights Commission noted that:

*There was agreement among submissions from all groups on consumers' entitlement to access private health records, and with notably few exceptions*

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<sup>29</sup> *Report of the Inquiry into the Use of Pituitary Derived Hormones in Australia and CJD*, pp 703-4.

<sup>30</sup> *Open Government: A Review of the Federal Freedom of Information Act 1982*, Australian Law Reform Commission Report No 77 and Administrative Review Council Report No 40, 1995, p 207.

<sup>31</sup> Queensland. Health Rights Commission. *Code of Health Rights and Responsibilities: A Discussion Paper*, December 1994, pp 3-4.



*respondents supported extension of freedom of information provisions to the private health sector.*<sup>32</sup>

The draft Code developed by the Commission applied across the public, community and private health sectors, and guaranteed a right of access to one's personal health records except in circumstances where an exception is provided for by law (eg as in the provisions of Qld's Freedom of Information Act which exempt the disclosure of information where it may endanger a person's life or safety, or is prejudicial to their physical or mental health or well-being) (para 6.1 of the draft Code).

In the 5<sup>th</sup> Annual Report 1996/97 of the Health Rights Commission, the Commissioner expressed concern that:

*... a Code of Health Rights and Responsibilities has not been accepted for implementation. Part 3 of the Act required the Commissioner to develop a Code of Health Rights and Responsibilities within three years after the commencement of the Act. This was done. However, neither the present nor previous Governments accepted the proposed Code. Discussions are being conducted with the current Minister in an endeavour to develop a revised draft acceptable to the Government.*<sup>33</sup>

In the 6<sup>th</sup> Annual Report 1997/98 of the Health Rights Commission, the Commissioner reported that, following the Queensland election on 13 June 1998, discussions were begun with the new Minister for Health, Hon Wendy Edmond MLA, regarding the composition of a Code. At the time of publication of the 1997/98 Annual Report, a proposal to redraft the Code was under consideration for submission to the Minister.<sup>34</sup>

## **5.5 REPORT OF THE SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE**

On 13 December 1996, an amendment was moved in the Australian Senate to the Health Insurance Amendment Bill (No 2) 1996 relating to patient access to medical records. The amendment, sought by Senator Neal, attempted to establish a scheme of national application creating a patient's right of access to medical records. The amendment proposed that a health care provider could decline to allow access to medical records if the provider reasonably believed that permitting access would be likely to cause serious harm to an individual's mental or physical well-being. Provision was also made for a patient to ask for his or her medical record to be

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<sup>32</sup> *Code of Health Rights and Responsibilities: A Discussion Paper*, p 41.

<sup>33</sup> Queensland. Health Rights Commission, 5<sup>th</sup> Annual Report 1996/97, p 5.

<sup>34</sup> Queensland. Health Rights Commission, 6<sup>th</sup> Annual Report 1997/98, pp 1-2.

corrected and if the physician disagreed, to have a note made in the record of the matters the applicant considered to be incorrect.<sup>35</sup>

Although the amendment was negatived, the issue was referred, for inquiry and report, to the Community Affairs References Committee on 14 December 1996. The Committee invited submissions from parties involved with, or having a representative interest in, access to medical records and received 60 submissions in all. Public hearings were also held in Sydney on 7 April 1997 and Canberra on 12 April.<sup>36</sup>

In its Report, issued in June 1997, the Committee recommended, inter alia,:

- that the framing of comprehensive national legislation providing a right of access to medical and other health records in the public and private sectors be commenced without delay
- that access under medical and other health records legislation should be prospective in its operation, except where matters of fact are concerned, in respect of which there should be a right of access, whenever the records were prepared
- that exemptions to access should be restricted to circumstances where a medical or health service provider was of the opinion that allowing access would be likely to cause serious harm to the mental or physical well-being of the patient/applicant, or to a third party, or to the privacy of a third party, and that such claims should have to be supported by evidence
- that reasons for exemptions and refusal to give access to medical or other health records should be stated to the applicant, and that exemptions should be fully supported with evidence which should be provided to the applicant
- that if a patient wished to challenge a refusal to grant access to a medical or other health record, then an appeal mechanism through an independent appeal body should be available.<sup>37</sup>

## 6. LEGISLATIVE REFORM IN AUSTRALIA

To date, the Australian Capital Territory is the only jurisdiction in Australia providing patients with a specific statutory right of access to their health records. The *Health Records (Privacy and Access) Act 1997*, which came into effect on 1

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<sup>35</sup> Australia. Parliament. *Senate Hansard*, Senator Neal, 13 December 1996, pp 7663-65.

<sup>36</sup> Report of the Senate Community Affairs References Committee, *Access to Medical Records*, June 1997, pp 1&4.

<sup>37</sup> Report of the Senate Community Affairs References Committee, *Access to Medical Records*, pp ix-xi.

February 1998, allows consumers a general right of access to health records which relate to them, subject to some limitations.

Consumers may exercise their right of access by:

- inspecting the record;
- receiving a copy of the record;
- viewing the record and having its contents explained by the record keeper or another suitably qualified health service provider: s 10(3).

In certain circumstances, detailed in s 14 of the Act, records do not have to be produced:

- if the record is not in the possession, custody or control of the record keeper
- if the record does not relate to the consumer
- if access would contravene an ACT or Commonwealth law or a court order.

Access is also prohibited:

- if the record keeper believes on reasonable grounds that providing the information in the record would constitute a significant risk to the life or the physical, mental or emotional health of the consumer (s 15(a)) or another person (s 15(b)). (Where s 15(a) applies, provision is made under the Act for a suitably qualified health service provider to discuss the record with the consumer if this is considered to be desirable: s 16.)
- if the record is subject to confidentiality: s 17.

An avenue is available for complaints to be made about a refusal to grant access to a medical record: s 18(3). Such complaints can be directed to the ACT Community and Health Services Commissioner and will be dealt with under the *Community and Health Services Complaints Act 1993*: s 18(3) and 19(1).<sup>38</sup>

## 7. OVERSEAS DEVELOPMENTS

### 7.1 UNITED KINGDOM

In the United Kingdom, the introduction of the *Access to Health Records Act 1990* followed a decision handed down by the European Court of Human Rights in *Gaskin v United Kingdom* (1989) 12 EHRR 36 in which it had been held that a decision to refuse an applicant access to certain health records had breached the applicant's right to respect for his private and family life as set out in Article 8 of the

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<sup>38</sup> 'Access to medical records - landmark legislation', pp 35-36.

European Convention for the Protection of Human Rights and Fundamental Freedoms 1950.<sup>39</sup>

Since 1984, the *Data Protection Act* (UK) had already allowed individuals access to computer-held information about themselves. Under the Access to Health Records Act, which came into effect in November 1991, patients are given a right of access to their own manually held records, unless access:

- is likely to cause serious harm to the patient's physical or mental harm or that of another individual: s 5(1)(a)(i)
- would identify another person who had supplied information in confidence: s 5(1)(a)(ii), unless that individual has consented to the application for access, or is a health professional who has been involved in the patient's care: s 5(2).

An applicant for access under the UK legislation is entitled to inspect his or her medical record, or an extract (if the right of access is partially excluded in accordance with s 5), and must be supplied with a copy thereof, if he or she requires it: s 3(2). If information contained in a record or extract is not intelligible without explanation, the Act also requires an explanation to be provided: s 3(3).

The right of access does not extend to information collected before the Act came into force: s 5(1)(b), unless giving access is necessary to make intelligible any part of a health record to which access is required to be given under the Act.

The UK Act makes provision for application to be made to a court where a record-holder has failed to comply with the requirements laid down in the Act: s 8.

The case of *R v Mid Glamorgan Family Health Services Authority* [1995] 1 All ER (before the English Court of Appeal) subsequently confirmed that, at English common law, there was no right of access to records pre-existing the Access to Health Records Act. In that case, the applicant needed to show that he was entitled to disclosure at common law, as the personal medical records he sought were in writing (and were therefore not subject to the Data Protection Act) and had been made before 1 November 1991 (and were therefore not subject to the Access to Health Records Act). The court held that a doctor or health authority, as the owner of a patient's medical records, was entitled to deny the patient access to them if it was in the patient's best interests to do so (for example, if their disclosure would be detrimental to the patient's health). An offer had been made by the solicitor for the respondent health authorities, to disclose the records to a medical practitioner nominated by the applicant, who could then judge whether the information in the records was likely to cause the applicant harm. This was held by the court to be a complete answer to the applicant's request for disclosure of his psychiatric records.

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<sup>39</sup> *Breen v Williams* (High Court), per Dawson & Toohey JJ at p 276.

### 7.1.1 Impact of the United Kingdom Legislation

Evidence about the impact of the Act in the early years of its operation has suggested that few patients were availing themselves of the opportunity to see and read their notes. According to an account in an article by Nigel Duncan, published in *Australian Medicine* in April 1995, one such survey, conducted at a Scottish hospital, found that during the UK Act's first year of operation, only three patients had requested access to their notes. In another study of 4 GP practices in London, cancer patients' reactions to enhanced access to their medical records was studied. Despite doctors' fears that greater access would worry patients and undermine patients' trust in their doctors, and that patients would wrongly interpret the content of medical records, it was found that most patients involved in the study had looked at their notes and most had found them informative and reassuring, adding to patients' understanding of the process they were undergoing and to their confidence. Summing up, Duncan states:

*The surprising thing is that in more than three years there has been so little reaction to the Act and so little evidence about its operation. There are several conclusions that can be drawn from this. The first is that very few patients have taken the opportunity to read their notes - a conclusion which is borne out by talking to GPs in general. The second is that where GPs are showing patients their notes, it is causing few problems and may even be improving the quality of the patient-doctor communication and quality of care.*

*The third conclusion that might be reached - although there is as yet no evidence to support this - is that doctors are changing the way in which they are writing notes.*<sup>40</sup>

## 7.2 NEW ZEALAND

In New Zealand, the *Privacy Act 1993*, and the Health Information Privacy Code 1994, provide patients with a right of access to their medical records.

The NZ Privacy Act gives the Privacy Commissioner the power to issue codes of practice modifying the Information Privacy Principles set out in the Privacy Act, in order to take into account the special characteristics of particular industries, agencies or kinds of personal information: s 46. A code of practice was issued for the health sector with particular characteristics of the health sector and health information in mind, such as the fact that health information is recognised as being highly sensitive and much health information is collected in a situation of confidence and trust. The Privacy Commissioner issued a temporary code of practice for the health sector under the Privacy Act in July 1993. The temporary code was replaced

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<sup>40</sup> Nigel Duncan, 'On the record', *Australian Medicine*, 7(6), 3 April 1995, p 13.

by the Health Information Privacy Code which commenced operation on 30 July 1994.<sup>41</sup>

Under the Act and accompanying code, New Zealanders possess the right to obtain personal health information about themselves held by health professionals (including doctors, dentists, pharmacists, nurses and psychiatrists), public and private hospitals, nursing homes, outpatients' clinics and ambulance services.

The guiding principle is that information is to be made available unless a reason exists under the legislation for withholding it (eg that the disclosure would be likely to prejudice the physical or mental health of the person requesting it). Even if information was withheld for the reason just stated, only the specific information considered likely to prejudice the person's health could be withheld, rather than the entire document.<sup>42</sup>

A complaint can be made to the Privacy Commissioner if reasonable access to one's records is refused, or one's request for correction of personal information is refused and there is no proper basis for the decision.<sup>43</sup>

### 7.3 UNITED STATES

Kirby P has described how in the United States, case law extended the fiduciary relationship to doctor and patient in a series of cases,<sup>44</sup> and this was later given effect to in legislation with nation-wide applicability.

In *Emmett v Eastern Dispensary and Casualty Hospital* (1967) 396 F 2d 931 a son sought access to hospital and medical records about his deceased father. The claim was upheld on the basis of the fiduciary nature of the relationship between the deceased and his physicians, with the court stating:

*We find in the fiducial qualities of that relationship the physician's duty to reveal to the patient that which in his best interests it is important that he should know.*<sup>45</sup>

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<sup>41</sup> New Zealand. Office of the Privacy Commissioner, "Health Information Privacy Code 1994", Fact Sheet No. 10, Internet item: <<http://www.knowledge-basket.co.nz/privacy/people/fact10.html>>

<sup>42</sup> "You and your health records", Internet item: <[http://www.womens-health.org.nz/html/health\\_records.html](http://www.womens-health.org.nz/html/health_records.html)>

<sup>43</sup> New Zealand. Office of the Privacy Commissioner, "Complaints", Fact Sheet No 6, <<http://www.knowledge-basket.co.nz/privacy/people/fact6.html>>

<sup>44</sup> *Breen v Williams* (NSW Court of Appeal), per Kirby P at p 544.

<sup>45</sup> quoted in *Breen v Williams* (NSW Court of Appeal), per Kirby P at p 544.

The court held that the record-keeper was obliged to place the medical records at the son's disposal and that the son should not be obliged to take legal proceedings to obtain them.

This case was followed in *Cannell v Medical and Surgical Clinic* 315 NE 2d 278 (1974), in which the Appellate Court of Illinois held that the fiducial qualities of the doctor-patient relationship required that medical data be disclosed to a patient or his or her agent on request.<sup>46</sup>

In 1995, the *Medical Records Confidentiality Act* passed by the US Senate in 1995 gave statutory recognition to a right of access by patients to their medical records. The Act allows consumers to inspect and copy their medical records, subject to certain exceptions (eg that disclosure could reasonably be expected to endanger the life or physical safety of any person, that someone who provided information in confidence may be identified, or that the information sought is used only for administrative purposes): s 101. Consumers may also seek to have information corrected or amended: s 102.

## 7.4 CANADA

In *McInerney v MacDonald* 93 DLR (4<sup>th</sup>) 415, the Canadian Supreme Court held that a patient is entitled to reasonable access to a doctor's records about the patient in order to examine and copy them. In this case, the respondent patient, Mrs MacDonald, had been treated by several doctors before being treated by the appellant physician Dr McInerney. On Dr McInerney's advice, Mrs McDonald stopped taking thyroid pills that had been previously prescribed by other physicians. She then requested the contents of her complete medical file from Dr McInerney. The doctor handed over copies of all notes and reports that she had herself prepared but refused to produce copies of the reports and records that she had received from other physicians.

An application to the courts for an order directing Dr McInerney to provide a copy of the entire medical file was granted. Appeals to the Court of Appeal and to the Supreme Court of Canada were dismissed. The Canadian Supreme Court handed down a joint judgment by La Forest, L'Heureux-Dube, Gonthier and Iacobucci JJ (delivered by La Forest J).

While accepting that the physician, institution or clinic which compiles the medical records owns the physical records, the court held that the patient has a vital and continuing interest in the information contained in his or her medical records, and in

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<sup>46</sup> as discussed in *Breen v Williams* (NSW Court of Appeal), per Kirby P at p 545.

controlling access to it.<sup>47</sup> As the patient's interest is in the information, it follows that the interest continues when that information is conveyed to another doctor who then becomes subject to the duty to afford the patient access to that information.<sup>48</sup>

La Forest J, delivering the unanimous judgment of the court, said that a refusal to disclose records may be warranted only if there is real potential for harm either to the patient or a third party, and the onus lies on the physician to justify a refusal.<sup>49</sup>

*Although the doctor in the case had conceded that a patient has a right to be advised of information about his or her health contained in the physician's medical records, the court found that the fiducial qualities of the doctor-patient relationship further extend the physician's duty to include the obligation to grant access to the information the doctor uses in administering treatment (ie to records that a physician may have received which were prepared by other physicians).<sup>50</sup>*

La Forest stated:  
*... information about oneself revealed to a doctor acting in a professional capacity remains, in a fundamental sense, one's own. The doctor's position is one of trust and confidence. The information conveyed is held in a fashion somewhat akin to a trust. While the doctor is the owner of the actual record, the information is to be used by the physician for the benefit of the patient. The confiding of the information to the physician for medical purposes gives rise to an expectation that the patient's interest in and control of the information will continue. ... The trust-like 'beneficial interest' of the patient in the information indicates that, as a general rule, he or she should have a right of access to the information and that the physician should have a corresponding obligation to provide it.<sup>51</sup>*

Although Kirby P in the NSW Court of Appeal found La Forest J's analysis of a doctor's fiduciary duty to provide access to medical records "*wholly convincing*",<sup>52</sup> the Canadian precedent was ultimately rejected by the High Court of Australia in *Breen v Williams* (see Section 4.3 of this Bulletin).

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<sup>47</sup> *McInerney v MacDonald* 93 DLR (4<sup>th</sup>) 415 at p 422.

<sup>48</sup> *McInerney v MacDonald* at p 425.

<sup>49</sup> *McInerney v MacDonald* at p 427 and pp 429-30.

<sup>50</sup> *McInerney v MacDonald* at p 424.

<sup>51</sup> *McInerney v MacDonald* at pp 424-25.

<sup>52</sup> *Breen v Williams* (NSW Court of Appeal), per Kirby P at p 545.



## 8. FIGURES ON ACCESS

According to the Public Interest Advocacy Centre, the number of requests for access to medical records is not recorded in Australia, England or New Zealand, although anecdotal evidence suggests the number of requests remains small. Based on their experience and a small survey conducted among general practitioners in 1994, the Office of the New Zealand Privacy Commissioner stated:

*... many GPs practices would not receive an access request at all during the year and others would be unlikely to get more than three. As knowledge of the new rights increases it is to be expected that more people will seek access ... if you were to approach practitioners themselves at random I would be confident you would strike many who have not had to handle a single request in three years since the Act came into force. Others you would find had always had an attitude of openness towards their clients and are delighted to make access available.<sup>53</sup>*

Probably because access to records is not seen as a right, health complaints commissions also report a low level of complaints. However, in NSW an increase in the number of complaints about access to medical records has been reported. The number of complaints to the NSW Health Complaints Unit increased from 28 in 1990-91 to 46 in 1993-94. In 1994-95, complaints to the NSW Health Care Complaints Commissioner comprised 43% of the total of 60 complaints.<sup>54</sup>

In Queensland, the Health Right Commission records the primary reasons for complaints as stated by consumers under six main categories: treatment, communication, rights (including access to records), access to health services, administration and costs. Of the 930 complaints closed in 1997/98, only 14 (1.5%) complaints concerned access to records.<sup>55</sup>

## 9. REASONS FOR SEEKING ACCESS

Case studies compiled by the Public Interest Advocacy Centre suggest that consumers seek access to their medical and health records for a variety of reasons, including the following:

- so that they may check the accuracy of the records
- in order to better understand their illness
- to better enable them to exercise control over their own treatment

<sup>53</sup> quoted in PIAC, *Whose Health Records?*, p 19.

<sup>54</sup> PIAC, *Whose Health Records?*, p 19.

<sup>55</sup> Queensland. Health Rights Commission, *6<sup>th</sup> Annual Report*, Table 4, "Primary Issues in Complaints Received", p 20.

- in order to compile family medical histories
- in the course of pursuing a complaint or instituting legal action against a health care provider, at which point they can become distressed to find that they do not have an enforceable right of access.<sup>56</sup>

## 10. THE MERITS OF ACCESS

Key arguments advanced for and against consumers having access to their medical records are discussed below:

### 10.1 ARGUMENTS AGAINST

- The quality of the records will suffer with health care providers sacrificing directness and clarity for diplomacy.<sup>57</sup> Or, as Australia's then Privacy Commissioner Kevin O'Connor explained, there is concern that "*records will become less frank, candid or informative if they can be seen by the subjects*".<sup>58</sup> On this point, Krever J in the *Canadian Report of the Commission of Inquiry into the Confidentiality of Health Information* stated:

... I do not believe that any responsible and ethical physician would omit from a medical record any information that, in the interests of proper medical care, belongs in it because of the possibility that the patient may ask to inspect it.<sup>59</sup>

- Consumers will not understand the contents of their records. However, it is always open for a consumer to obtain assistance in understanding his or her medical records. In the *Canadian Report of the Commission of Inquiry into the Confidentiality of Health Information*, it was suggested that it might be necessary to re-evaluate record-keeping methodology if a general rule of access was established.<sup>60</sup> Bloch et al, who found the use of abbreviations to be extensive in a random selection of psychiatric records they examined,

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<sup>56</sup> PIAC, *Whose Health Records?*, Chapter 3, pp 16-21.

<sup>57</sup> AMA submission and discussions with the Royal Australian College of General Practitioners, cited in PIAC, *Whose Health Records?*, p 23.

<sup>58</sup> Kevin O'Connor, Privacy Commissioner, 'Information Privacy Issues in Health Care and Administration', Inaugural National Health Informatics Conference, Brisbane, 4 August 1993.

<sup>59</sup> *Report of the Commission of Inquiry into the Confidentiality of Health Information*, Toronto, Ontario, 1980 (Krever Report), vol 2, p 457, quoted in *McInerney v MacDonald* at p 429.

<sup>60</sup> Krever Report, vol 2, p 469 cited in *McInerney v MacDonald* at p 429.

suggested, as a simple solution, that a list of common abbreviations in medicine be placed at the front of each set of medical notes.<sup>61</sup> If there is a possibility that a patient may misinterpret information contained in a record (such as the results of laboratory tests), the doctor may wish to advise the patient that a competent health care professional should explain and interpret the medical record<sup>62</sup> (see also the comments below regarding FOI provisions).

- Flowing from concerns that consumers will not understand or will misinterpret their medical records are fears that consumer's worries and anxieties will be increased. In *Breen v Williams*, Dr Williams had expressed concern that his patients would be caused confusion, stress and worry if their medical records were made available to them without adequate explanation.<sup>63</sup> The Australian Medical Association and the Royal Australian College of General Practitioners advanced similar arguments to the Public Interest Advocacy Centre's project, while consumer submissions from the New South Wales Medical Consumers Association and Disabled People International (Tasmania) argued that access needs to be treated sensitively as consumers have found seeing their health records traumatic.<sup>64</sup> Particularly in the case of psychiatric records, it has been suggested that access to records should be arranged in conjunction with a medical professional.<sup>65</sup> Such concerns have specifically been addressed in existing freedom of information legislation by the inclusion of provisions whereby access to medical records is allowed through a nominated medical practitioner in circumstances in which it might be detrimental to a patient's mental or physical well-being for direct access to be granted. Another possible precedent, is that found in the Council of Europe Draft Recommendation on the Protection of Medical Data issued for comment in July 1992, which provides for an individual to nominate another person to act on their behalf in receiving information from a health professional.<sup>66</sup>

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<sup>61</sup> Sidney Bloch, Claire E Riddell and Tasmin J Sleep, 'Can patients safely read their psychiatric records?: Implications of freedom of information legislation', *Medical Journal of Australia*, 161(11/12), 5/19 December 1994, pp 665-666 at p 665.

<sup>62</sup> discussed in *McInerney v MacDonald* at pp 428-429.

<sup>63</sup> see Dr Williams' comments, as quoted in Kirby P's judgment in *Breen v Williams* (NSW Court of Appeal) at p 529.

<sup>64</sup> PIAC, *Whose Health Records?*, p 23.

<sup>65</sup> Bloch, Riddell and Sleep, pp 665-666.

<sup>66</sup> O'Connor, pp 9-10.

- Consumers being allowed access to records will lead to an increase in litigation. However, in *McInerney v MacDonald*, La Forest J said:

*The argument that patients may commence unfounded litigation if they are permitted to examine their medical records is not a sufficient ground for withholding them. The comments of Eberle J. in Strazdins v Orthopaedic & Arthritic Hospital Toronto (1978), 7 C.C.L.T. 117 at pp.119-20 ... are helpful in this regard. He states:*

*... I believe that it is part of our system of government and of the administration of justice that persons are entitled to start law suits against persons whom they feel have wronged them. The persons who start such actions do so at the risk of costs, the risk of having the action dismissed at some stage if it turns out that it is groundless or even if not groundless turns out to be unsuccessful ... I am not forgetting that if any particular person makes a habit of starting groundless law suits or repetitive law suits against a particular person or persons, there are controls which may be exercised to prevent such matters from occurring.<sup>67</sup>*

Once litigation is commenced, a patient can generally obtain his or her medical records under the rules relating to discovery of documents. In *Breen v Williams*, it was common ground between the parties that if Mrs Breen was to commence proceedings against the manufacturer of her breast implants, she would be able to obtain access to Dr Williams' records by compulsory court process (eg via an order for discovery, or by way of letters rogatory), subject to the court's discretion.<sup>68</sup> (However, in that case, Mrs Breen wished to test her right to access her records without having to obtain a court order).<sup>69</sup>

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<sup>67</sup> *McInerney v MacDonald* at p 428.

<sup>68</sup> *Breen v Williams* (High Court), p 267.

<sup>69</sup> Julie Hamblin, 'Breen v Williams: Right of access to medical records denied', *Privacy Law & Policy Reporter*, 1 (8), October 1994, pp 141-42, 158, at p 141.

According to La Forest J, refusing a patient access to his or her records may actually encourage groundless litigation:

*... if a patient strongly wishes to see his or her records, one way of achieving this result is to commence an action before ascertaining whether or not there is a valid basis for the action.*<sup>70</sup>

## 10.2 ARGUMENTS FOR

- Consumers will better understand their health problems and communication between the consumer/patient and the medical or health care provider will be improved. In three American studies reviewed by Bergen, more than two-thirds of consumers said they were able to better understand their health problems after reading their medical records.<sup>71</sup>
- An availability of a right of access may make record-keepers more accountable for the accuracy and sufficiency of their records. Contrary to the supposition that allowing consumers to see their records will lead to a reduction in their quality, with doctors perhaps reluctant to record mere speculative comments,<sup>72</sup> the Health Information Management Association of Australia suggested, in its submission to the Senate Community Affairs References Committee, that a very strong correlation existed between access to medical records and improved quality.<sup>73</sup>
- Consumers will be able to improve the quality of the record by ensuring the information it contains is accurate and relevant, a matter of increasing importance as medical records have come to be used for a wider range of purposes. As Westin points out in *Computers, Health Records and Citizen Rights*:

*As to medical records, when these were in fact used only by the physician or the hospital, it may have been only curiosity when patients asked to know their contents. But now that medical records are widely shared with health insurance companies, government payers, law enforcement agencies, welfare departments, schools, researchers, credit grantors, and employers, it is often crucial for the patient to know what*

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<sup>70</sup> *McInerney v MacDonald* at p 428.

<sup>71</sup> L Bergen, 'Patient access to medical records: a review of the literature', *AMR Journal*, 18(3), September 1988, p 102 at p 103, cited in PIAC, *Whose Health Records?*, p 22.

<sup>72</sup> PIAC, *Whose Health Records?*, p 22.

<sup>73</sup> Transcript of Evidence by the Health Information Management Association of Australia (HIMAA), p 95, cited in Report of the Senate Community Affairs References Committee, *Access to Medical Records*, p 33.

*is being recorded, and to correct inaccuracies that may affect education, career advancement or government benefits.*<sup>74</sup>

- It will be easier to ensure continuity of care and coordination between health care providers if a patient moves or change doctors.<sup>75</sup> As was pointed out in *McInerney v MacDonald*, the practice of modern medicine tends to favour involvement with or referral to a number of professionals (one's personal physician, medical specialists, technologists and technicians, and allied health care professionals):

*Each of the pieces of information provided by this 'army' of health care workers joins with the other pieces to form the complete picture. If the patient is only entitled to obtain particular information from each health care provider, the number of contacts he or she may be required to make may become enormous. The problem is intensified when one considers the mobility of patients in modern society.*<sup>76</sup>

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<sup>74</sup> AF Westin, *Computers, Health Records and Citizen Rights*, Petrocelli Books, New York, 1976, p 27, quoted in *McInerney v MacDonald* at p 422.

<sup>75</sup> PIAC, *Whose Health Records?*, p 22.

<sup>76</sup> *McInerney v MacDonald* at p 421.

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- New Zealand. Office of the Privacy Commissioner, “Complaints”, Fact Sheet No 6, <<http://www.knowledge-basket.co.nz/privacy/people/fact6.html>>
- New Zealand. Office of the Privacy Commissioner, “Health Information Privacy Code 1994”, Fact Sheet No. 10, Internet item: <<http://www.knowledge-basket.co.nz/privacy/people/fact10.html>>
- “You and your health records”, Internet item: <[http://www.womens-health.org.nz/html/health\\_records.html](http://www.womens-health.org.nz/html/health_records.html)>

## CASES

- *Breen v Williams* (1994) 35 NSWLR 522.
- *Breen v Williams* (1996) 138 ALR 259.
- *Cannell v Medical and Surgical Clinic* 315 NE 2d 278 (1974)
- *Emmett v Eastern Dispensary and Casualty Hospital* (1967) 396 F 2d 931
- *McInerney v MacDonald* 93 DLR (4<sup>th</sup>) 415.
- *R v Mid Glamorgan Family Health Services Authority and another, ex parte Martin*[1995] 1 All ER 356.
- *Rogers v Whitaker* (1992) 109 ALR 625.

## LEGISLATION

### Commonwealth

- *Freedom of Information Act 1982*

### Queensland

- *Freedom of Information Act 1992*
- *Health Rights Commission Act 1991*

**New South Wales**

- *Freedom of Information Act 1989*
- Private Hospitals Regulation 1996
- Day Procedure Centres Regulation 1996
- Nursing Homes Regulation 1996

**Victoria**

- *Freedom of Information Act 1982*
- *Health Services (Conciliation and Review) Act 1987*

**South Australia**

- *Freedom of Information Act 1991*

**Western Australia**

- *Freedom of Information Act 1992*
- *Health Services (Conciliation and Review) Act 1995*

**Tasmania**

- *Freedom of Information Act 1991*

**Australian Capital Territory**

- *Freedom of Information Act 1989*

**New Zealand**

- *Privacy Act 1988*
- *Health Information Privacy Code 1994*

**United Kingdom**

- *Access to Health Records Act 1990*

**United States**

- *Medical Records Confidentiality Act 1995*

- **APPENDIX A - NEWSPAPER ARTICLES**

**Title** Court bid for medical files.

**Author** Denholm, Matthew

**Source** Courier Mail

**Date Issue** 22/11/95 **Page** 11

Patients' rights to see their medical records may be overridden by doctors' rights to copyright, the High Court heard yesterday. Justice Michael McHugh raised the issue in a case in which a former model allegedly injured by a leaky breast implant is seeking access to her medical records. The test case, if successful, would benefit thousands of Australian women suing breast implant manufacturers in the United States. It would also enshrine the right of all Australians to see their doctors' records. Justice McHugh said doctors had a statutory right to copyright and that the issue was significant in the appeal case. Peter Cashman, counsel for former NSW model Julie Breen, urged the Full Court not to let copyright stand in the way of patients' rights. "It would be an odd situation if the law of copyright prevented the patient from getting back information she provided to the doctor," he said. However, Justice McHugh said medical records included input from doctors, not just information provided by the patient. The issue was taken up by lawyers for the doctor, Cholmondeley Williams, who argued there was nothing in the doctor-patient relationship which removed doctors' copyright. Ms Breen is appealing a NSW Court of Appeal decision that she did not have a right to see her medical records. The 39-year-old mother of four is one of more than 2000 Australian women suing silicone US breast implant manufacturers over injuries they allegedly caused. To be in the running for a \$US4.2 billion settlement, the women must file copies of their medical records.

Dr Williams, who operated on Ms Breen for complications allegedly related to the implants in 1978, refused to allow her access to her records. He offered to give her a report on what was in the records, but only if she released him from any legal claim. Ms Breen's lawyers also have to convince the Full Court that doctors do not own their patient records. "We're saying doctors do not own records or information created for the patient's benefit," Mr Cashman said. "If it's anyone's property, it is the property of the patient.".. Dr Williams's counsel, Sydney QC Arthur Emmett, said there was no common law right for patients' to see or copy their records. Mr Emmett likened the situation to banking, where a customer was entitled to be told the status of their account - but not to inspect the bank's records. Both lawyers clashed over whether doctors had an ethical duty to hand over patient records. The court reserved its decision.

**Title** Test case on access to medical records.

**Author** FIFE-YEOMANS, JANET

**Source** Australian

**Date Issue** 17/01/95 **Page** 5

THE High Court has been asked to decide if patients have a right to access to their medical records held by general practitioners and private specialists in a test case supported by consumer, community and advocacy groups. The challenge to the law has been lodged by Ms Julie Breen, who has been fighting for access to her medical files from the doctors and specialists she has seen with problems concerning her silicone breast implants. Ms Breen's solicitors have filed documents seeking a right to appeal to the High Court against a decision by the NSW Court of Appeal on December 23 which ruled against Ms Breen and in favour of the medicos. In the document filed with the High Court, Ms Breen has argued that the court was wrong to find she had no legal right of access to the medical records. Access to medical files is available to patients who received treatment in public hospitals and the Australian Law Reform Commission is considering if public freedom of information laws should be extended to the private arena. Ms Breen's solicitor, Ms Vera Culkoff, of the law firm Cashman & Partners, said Australia lagged behind countries such as the United States, the United Kingdom, Canada and New Zealand, where the right of access to all medical files exists. "If we are unsuccessful in the High Court, our only recourse is legislation," said Ms Culkoff. "I have no doubt that legislation will be enacted but the wheels run slowly and we thought the courts were the ideal way to get the issue decided once and for all.". Ms Breen first sought access to her files six

years ago for legal action she is taking in the US over her silicone implants. The doctor against whom she has brought her test case had offered to provide her with her medical files only if she was willing to release him from any legal claim arising from the treatment. She refused. The alternative was to force him to produce the files through a court subpoena, a costly and cumbersome procedure which entails launching a legal action first, a practice Ms Breen decided to challenge. The doctor's argument was supported by his insurers, the NSW Medical Defence Union. The documents lodged with the High Court argue that the patient's right to such information should not be determined solely at the individual doctor's subjective discretion. The president of the NSW Medical Defence Union, Dr Richard Tjong, said the High Court challenge would be opposed. "If it could be demonstrated that there has been change in public expectation and if this public expectation is that doctors give full and free access to medical records, then the law should be changed to accommodate that ... it should be changed not by common law (through the courts) but by legislation," Dr Tjong said.

**Title** Medical records to remain with doctors.

**Author** SOLOMON, DAVID

**Source** Courier Mail

**Date Issue** 07/09/96 **Page** 2

THE High Court has unanimously decided that patients do not have an automatic right to medical records compiled by their doctors. Yesterday it rejected an appeal by Gold Coast woman Julie Breen, 40, who had sought medical records prepared by Sydney surgeon Cholmondeley Williams. Ms Breen consulted Dr Williams in the year after another doctor had inserted silicone implants in her breasts. The implants were later removed by a third surgeon. She sought her records from Dr Williams when she became involved in a class action in the United States against the company which manufactured the implants. Dr Williams offered to provide her with the records if she would undertake not to make any claim against him over his treatment of her. Alternatively he offered to provide her with all the information in the records, but not to set out the full text of what he had written in them. Ms Breen rejected both offers. According to members of the High Court she could have obtained the records for the purpose of the US case by using compulsory court processes, as other litigants had done, but she wanted instead to assert a right as a patient to get the records other than for the purpose of court proceedings. However, the High Court decided that the records were the property of the doctor, not of the patient. Justices Sir Daryl Dawson and John Toohey said in a joint judgment that the doctor's duty was to exercise reasonable care and skill in giving treatment and advice, and it was in carrying out this duty that he compiled his records. "In doing so," they said, "(the doctor) did not act as an agent for (Ms

Breen) and the documents were his property alone.". Justices Mary Gaudron and Michael McHugh said in their judgment that doctors may be restrained from using the information in their records to make an unauthorised profit or disclosing information to unauthorised people. Otherwise, they said, the records were the doctors, "to save or destroy". They said if there was to be any change in the law, it should be made not by the courts but by Parliament.

**Title** Medical records judgment sparks row over access.

**Author** FIFE-YEOMANS, JANET

**Source** Australian

**Date Issue** 07/09/96 **Page** 5

THE High Court yesterday ruled in an unpopular decision that patients have no right of access to their medical records held by their general practitioners. The pressure is now on the Federal Government to extend the Freedom of Information laws to the private sector, with the court's decision condemned by consumer and advocacy organisations, the Australian Law Reform Commission and the federal privacy commissioner. The Royal College of General Practitioners has implemented an interim policy which already allows patients access to their records if the result is better patient care. The six High Court judges were unanimous in their decision that patients had no such right in common law but they passed the buck when it came to changing the law. "There is more than one view upon the matter and the choice between those views, if a choice is to be made, is appropriately for the legislature rather than a court," said Justice Daryl Dawson and Justice John Toohey in a joint judgment. It had been mounted as a test case by a young mother, Mrs Julie Breen, who is suing over health problems associated with ruptured silicone breast implants. Traditionally, the only way patients have been able to see their files has been through a costly court subpoena, except in a public hospital where they are freely available under FOI laws. Ms Breen, 40, of Tweed Heads in northern NSW, thought that as a question of principle as well as law, she should be allowed to see her files without court intervention. "A claim that a patient has a right of access to his or her medical records is a question of

great social importance. But absent a contractual term, such a claim has no foundation in the law of Australia," said Justice Mary Gaudron and Justice Michael McHugh. "It is a serious constitutional mistake to think that the common law courts have authority to 'provide a solvent' for every social, political or economic problem ... If change is to be made, it must be made by the legislature." Ms Breen's solicitor, Ms Vera Culkoff, said the court had already made law in its Mabo decision among many other decisions, and there were legal hooks on which to hang a change in the present case. "It's an extraordinary decision. Julie is astounded. It's not in step with what contemporary Australian society expects," said Ms Culkoff, who described the current High Court, with the exception of Justice Michael Kirby, who did not sit on this case, as very conservative. "But I'm surprised that they were not a bit more adventurous and I disagree with them in principle." The commission has recommended that the issue of private medical records be one of the first areas to be legislated on in its report on extending the Privacy Act and Freedom of Information laws, currently with the federal Attorney-General, Mr Williams. Mr Williams will be making an announcement next week on extending the Privacy Act. However, the High Court's decision was applauded by the Australian Medical Association, which said doctors feared giving patients unfettered access to their records might compromise their ability to provide high-quality care.

**Title** Doctors fight against patient record access.

**Author** HAMMOND, PHILIP

**Source** Courier Mail

**Date Issue** 07/02/96 **Page** 7

QUEENSLAND doctors will fight moves for patients to have unlimited access to their medical records. They say it is a doctor's right "to deny access to the medical record to any patient whose health might be adversely affected as a result of such access.". The Australian Medical Association state branch this week set a policy that doctors were entitled not to give patients complete access to their medical records. The policy says patients are entitled to have made available to them a summary of medical information from the record, but access was not an absolute right. AMA state president Stephen Phillips said last night that cost and time was involved when patients sought information from their files. "There's going to be necessary time and administrative work involved and that costs money," Dr Phillips said. "The cost is going to have to be transferred to the patient in those circumstances.". Doctors are preparing to fight the access moves at state and federal level. Queensland's Health Rights Commission has a charter of patients rights, which favours patients' rights of access. A Federal Government spokesman confirmed yesterday that a High Court ruling over a New South Wales woman Julie Breen's test case would influence whether the law needed to be more specific. Dr Phillips said: "The important point we need to make is what the Breen side has been arguing and what some of the more aggressive consumerists argue and what unfortunately (Federal health minister) Dr Lawrence has been thinking about is

essentially carte blanche access to medical records.". For patients to have "by right" ownership of everything written down about them was "clearly unbalanced, clearly unfair and clearly ignoring the rights of doctors," he said. Dr Phillips said it was an unpalatable but true fact that in modern times, patients could be requesting full access to a doctor's medical records for medico - legal reasons. "We need to make sure sufficient safeguards exist so a doctor can make sure information in the record is transferred with appropriate interpretation," he said. Appropriate attention needed to be given to the protection of therapeutic privilege, Dr Phillips said.



**Title** Medical records opened in ACT.

**Author** JOPSON, DEBRA

**Source** Sydney Morning Herald

**Date Issue** 02/02/98 **Page** 3

Consumer groups claimed a "landmark" new law which took effect in the ACT yesterday, giving patients access to their own medical records in doctors' surgeries and private hospitals, was a victory that would put pressure on the Federal and State governments to follow. "This will clear the way for other States," said the president of the Health Care Consumers' Association of the ACT, Ms Janne Graham. "We couldn't get the Federal Government to take responsibility for it and so we are doing it this way, to show the sky won't fall in for the doctors.". The executive director of the national Consumers' Health Forum, Ms Kate Moore, said the law in NSW and other States restricting patient access to records held by private health providers was an "anachronism" and consumers would now step up their demands for change. But a lawyer who specialises in medical cases, Dr Maura McGill, said some doctors feared that lawyers would use the ACT's Health Records (Privacy and Access) Act to go on "fishing expeditions" for negligence cases. The Federal president of the Australian Medical Association, Dr Keith Woollard, claimed the law could be used by life insurance companies to make people provide their medical records. He was certain it would result in a court challenge because it was in conflict with a 1996 High Court decision. In that case, Ms Julie Breen, a former patient of a plastic surgeon, Dr Cholmondeley Williams, failed to win access to his files on her when the High Court found that a patient's medical record belonged to the private medical practitioner. Under the ACT law, which

Ms Graham claims followed a 24-year battle by consumer groups, patients can pay a fee (yet to be set) to see their records and take notes, get a copy of their records or have a qualified health worker explain them. Doctors face a \$5,000 fine and/or six months' jail for altering medical records. Dr McGill, a partner in the law firm Clayton Utz, predicted the ACT law would lead to doctors throughout Australia being more open with their patients about what they wrote in their records. "It is a very sensible process of trying to get doctors not to make ridiculous comments.". Dr Woollard said the new law was useless because it would be unusual for a doctor to reject a request from a patient to see personal medical records. "Wherever this legislation is in place, nobody uses it," he said. "For instance, in the UK, nobody wants it.". However, Ms Graham said she had four calls a week from people asking how they could access their medical records. A spokeswoman for the NSW Minister for Health, Dr Refshauge, said yesterday that his department would monitor the the ACT law's operation but would prefer "a co-ordinated national response". A spokesman for the Federal Minister for Health, Dr Wooldridge, said the Government would prefer doctors' organisations to introduce a code of practice "with teeth" on patients' access to medical records rather than national legislation. "Should it fail, we would consider legislation further down the track," he said. The Government would also consider the report of a Senate committee which is looking into the issue.

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