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[Mendelson, Danuta 2003, Travels of a medical record and the myth of privacy, Journal of law and medicine, vol. 11, no. 2, pp. 136-145.](#)

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Travels of a medical record and the myth of privacy

In his seminal work entitled *Computers, Health Records and Citizen Rights*, published in 1976, Westin wrote:

[T]he information gathering process in a hospital is just one factor out of many which tends to strip patients, both figuratively and literally.¹

One could say that in general, in Australia today, the concept of patients' confidentiality is strained, and the notion of patients' privacy illusory.² This column discusses medical records and patients' personal information contained therein from the perspective of confidentiality and privacy. This is done by tracing the travels of personal information contained in a medical record created in the process of diagnosis and treatment of disease, from the point of the original medical encounter with the primary carer to the many points outside the therapeutic environment and outside the knowledge of the patient where her or his personal information may be recorded or accessed. Only those methods and ways of accessing and processing personal information contained in medical records that are legal and sanctioned by legislation, including the *Privacy Act 1988* (Cth), the *Health Records (Privacy and Access) Act 1997* (ACT), the *Health Records Act 2001* (Vic), and the *Health Records and Information Privacy Act 2002* (NSW), are discussed.

The *Privacy Act 1988* (Cth), s 6, defines "personal information" as information or an opinion (including information or an opinion forming part of a database), whether true or not, and whether recorded in a material form or not, about an individual whose identity is apparent, or can reasonably be ascertained, from the information or opinion.³

The term "health information" is taken to mean: information or an opinion about the person's health or a disability (at any time); his or her expressed wishes about the future provision of personal health services; or a health service provided, or to be provided, to an individual; that is also personal information; other personal information collected to provide, or in providing a health service or donation of his or her body parts, organs or body substances.⁴

Furthermore, the definition of a "record" under s 6(1) of the *Privacy Act 1988* (Cth) includes a document; or a database (however kept); or a photograph or other pictorial representation of a

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person.⁵ Definitions in other statutes are not identical, but all encompass medical records in whatever form they happen to be kept.

The road map

This analysis of confidentiality and privacy relating to medical records is based on a scenario involving a legal "road map" of one patient's medical record. Westin⁶ conceptualised the flow of personal medical data into three zones:

- zone one: "primary care" provided by medical practitioners and other health care professionals;

- zone two: "supporting activities" by such entities as the Health Insurance Commission and private health insurance organisations, State and Territory accident benefits schemes, employers, and life and disability insurance;
- zone three: "social and other uses of health records data", where health information is used for the purposes of research, professional standards, civil litigation, and criminal proceedings.

This three-tier model has been adapted to Australian conditions.

Let's use the hypothetical example of Mrs Drocker. Mrs Drocker, a 31-year-old dental surgeon, visits Dr Gerald Pop (GP), her local general practitioner, because she is concerned about a reddish-purple lump under the knee of her left leg. Dr GP, who is employed by a privately owned medical clinic, does not like the look of it, and refers her for a biopsy to Mr PS, a plastic surgeon. In the process, Dr GP creates a medical record with personal information about Mrs Drocker, including her name, date of birth, personal status, address, and the site, signs and symptoms, as well as an undifferentiated diagnosis, of the tumour. Mr PS, who works in a public hospital, excises the tumour and sends a tissue sample to the DPL, an approved diagnostic and pathology laboratory. Through these actions, Mr PS creates a medical record relating Mrs Drocker's condition. The pathology results come back to Mr PS with the diagnosis of a rare cancer known as Kaposi's sarcoma.⁷ There is now a medical record by DPL of Mrs Drocker's pathology sample. A copy of the report is forwarded to Mr PS, who sends a letter, which is a form of medical record, to Dr GP confirming the diagnosis of Kaposi's sarcoma, and suggesting that further tests be done to see if there are any signs of Kaposi's sarcoma cells elsewhere in the patient's body.

During the consultation, Dr GP informs Mrs Drocker about the diagnosis of Kaposi's sarcoma. He also asks the patient a number of very sensitive questions, which are vital to the diagnosis of the aetiology, and therefore the type, of Kaposi's sarcoma. There are four types of Kaposi's sarcoma, which is also referred to as KS:

- The *classic* type of Kaposi's sarcoma is a very rare, slow-growing cancer, usually only found on the skin of legs and feet in older men of Mediterranean or Jewish descent, but may also appear in females (10 to 15 men are affected to every woman). Hence, it is important to know Mrs Drocker's ethnic origins. Mrs Drocker tells Dr GP that she is a devout Roman Catholic of Irish extraction.
- The *endemic* Kaposi's sarcoma is found in parts of equatorial Africa as well as in Italy and Greece. It develops more quickly than classic KS and can affect men, women and children of all ages.⁸
- *Transplant-related (acquired)* Kaposi's sarcoma usually occurs in people who have to take immunosuppressant drugs following an organ transplant (such as a kidney transplant). This form of KS may improve if the immunosuppressant drugs are reduced or stopped.⁹ Mrs Drocker has had no organ transplants and is not taking any immunosuppressant drugs.

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- *AIDS-related (epidemic)* Kaposi's sarcoma is the most common and the fastest developing form of the disease.¹⁰ It develops in people who are infected with the human immunodeficiency virus (HIV). Infection by HIV can be asymptomatic. The diagnosis of the acquired immune deficiency syndrome (AIDS) will only be diagnosed when the HIV virus has caused

serious damage to the patient's immune system resulting in certain types of medical conditions. One such "AIDS-defining condition" is Kaposi's sarcoma.

Significantly, infection with the Human Herpes Virus 8 (KSHV) has been linked to the development of all forms of KS.¹¹ Although this virus is particularly closely linked to AIDS, the endemic KS is also associated with the presence of the Human Herpes Virus-8 (HHV-8). Indeed, the seroprevalence of Human Herpes Virus-8 is estimated to be between 10 and 70% in the adult general population in countries of the Mediterranean basin and equatorial Africa, but is generally asymptomatic. Viral transmission, in endemic populations, seems to occur from mother to child and between siblings. Heterosexual transmission appears essentially to concern groups at risk for sexually transmitted diseases. Saliva is a major reservoir of HHV-8.¹² Aware of these facts, Dr GP refers Mrs Drocker to undergo blood tests to check for the presence of HIV and the Human Herpes Virus 8.

The DPL laboratory performs the blood tests, which show no presence of an HIV infection, but a presence of the Human Herpes Virus 8. The letter of referral written by Dr GP to Dr O, an oncologist in private practice, contains personal information about Mrs Drocker as well as the results of the two tests. Dr O refers Mrs Drocker for a battery of tests, including a chest X-ray, CT scan, endoscopy and lung-function tests to investigate the presence of KS in other parts of her body.

The presence of the Human Herpes Virus 8 (KSHV) in her blood upsets and puzzles Mrs Drocker. At a consultation with Dr O during which Mrs Drocker's husband is present, he is told of her condition and agrees to have a blood test for the Human Herpes Virus 8. It comes out clear. Both events are recorded in Mrs Drocker's records by Dr O, with a copy sent to Dr GP. Mrs Drocker has what is commonly called a "mental breakdown" and is admitted to a private psychiatric clinic by a psychiatrist, Dr Sana, who records not only her medical history, but also her feelings of anger and bitterness towards her husband.

Given the outcome of the blood tests, the husband accuses Mrs Drocker of adultery. He instructs his lawyer to initiate divorce proceedings, and to subpoena Mrs Drocker's records from Dr GP, Dr O and Dr Sana.

Let's examine the issues of privacy and confidentiality as they relate to Mrs Drocker's medical records. Mrs Drocker has provided explicit or implicit consent to the creation of these medical records, in the belief that the information collected therein will be used strictly for the purpose of her medical care. Since the doctors and the diagnostic and pathology services created them as a result of direct patient care for therapeutic purposes, they belong to "zone one".

Confidentiality and privacy

As a general rule, personal information contained in Mrs Drocker's medical records is protected by the ethical and legal principle that those who agree to receive information on the basis that it will be kept secret, come under the obligation of confidentiality.¹³ Confidentiality is an ethical principle, which has been conceptualised as a duty. The modern concept of a medical duty of confidentiality has

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its roots in the Western religious¹⁴ and secular ethical canon embodied in the Hippocratic Oath, the penultimate clause of which states:

[W]hat I see or hear in the course of the treatment or even outside of the treatment in regard to the life of men, which on no account one must spread abroad, I will keep to myself holding such things shameful to be spoken about.¹⁵

Written between 460 and 300 BCE, the Hippocratic Oath was the first known code of ethics and professional etiquette pertaining specifically to the medical profession.¹⁶ The confidentiality clause in the Oath imposed upon medical practitioners an obligation to keep confidential not only their observations about, and knowledge derived from, the patient in the course of a therapeutic relationship, but also any information gathered outside of their medical activity, if it related to the professional relationship with the patient. The wide scope of secrecy encompassed by the confidentiality clause aimed to protect the integrity of the therapeutic relationship by enabling doctors to expect truthful disclosure of personal information from patients, while reassuring patients that any information provided by them would remain secret.

Today, unless authorised by the patient or by statute, doctors and other health care providers are under a duty to abstain from disclosing information imparted to them in the course of a professional relationship. Professional duties of confidentiality are enforceable in equity through an action for breach of confidence;¹⁷ at common law, through the action for intentional infliction of psychiatric injury and in negligence;¹⁸ as well as through professional codes of ethics.¹⁹ All Australian States and Territories have numerous enactments mandating confidentiality of health information in specific circumstances.²⁰ Since the ethical and legal duty of confidentiality is owed by medical practitioners and other health care professionals to their patients, Mrs Drocker has the right to decide to whom her personal health information should be disclosed. For example, by agreeing to be referred to other doctors, she gave Dr GP implicit permission to provide the others with personal information about her. Likewise, by

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agreeing to the joint consultation with her husband, she implicitly provided Dr O with consent to the disclosure to the husband of information about her condition.²¹

Privacy

Privacy is a much wider concept than confidentiality. It relates less to interpersonal communications and more to the right to control information about oneself and the right to exclude others from accessing it.²² Whereas the legal concept of confidentiality reflects notions of trust embedded in the Judeo-Christian moral and ethical heritage, the concept of privacy is grounded in the notion of a personal right to self-determination. . As such, the term "privacy" is a misnomer because conceptually, "privacy addresses not secrecy, but the scope and limits of individual autonomy" and is based on a social and legal distinction between intimate and public domains.²³ The modern notion of privacy can be traced to the rise of economic and social hegemony of the bourgeoisie in the 19th century,²⁴ with its emphasis on personal independence

and a general right or liberty of individuals to have their private lives protected from public scrutiny.

In relation to personal information, the right to privacy has been defined as protecting "data which relates to and identifies an individual and which, it can be assumed, the individual would prefer not to be made available to unauthorised persons or for unauthorised purposes".²⁵ Legal theories of information privacy derive from the doctrine that a person has the right to control information about oneself.²⁶ German courts have coined a doctrine of "informational self-determination",²⁷ according to which every person has "the right to control 'the image of his personality' that is presented to others through the processing of his personal data".

Privacy – at present – is entirely a creature of statute. It is governed by the *Privacy Act 1988* (Cth), the *Health Records (Privacy and Access) Act 1997* (ACT), the *Health Records Act 2001* (Vic) and the *Privacy and Personal Information Protection Act 1998* (NSW). These legislative schemes are not dissimilar, insofar as one of their objects is to provide the patient with a degree of control over her or his medical or health information by restricting or prohibiting disclosure,²⁸ subject to a number of

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exceptions; and providing for patients' access to medical records.²⁹

Ten National Privacy Principles contained in the *Privacy Act 1988* (Cth) govern parts of the private sector and all health service providers in relation to collecting, storing, using and disclosing personal information. These national principles interact with State and Territory rules, providing a complex web of prohibitions on and exceptions to disclosure.³⁰ The exceptions to the prohibition of disclosure of personal information contained in medical records become particularly important in the context of zones two and three.

The right to privacy overlaps with the right to confidentiality insofar as both are based on the moral principle which provides that a recipient of "personal information" or data³¹ pertaining to another should not disclose it without the free consent of the person who is the subject of the information. However, since confidentiality and privacy are quite different concepts, it will become apparent from the discussion below that they do not necessarily co-exist. Within "zone one", Mrs Drocker's right to both confidentiality and privacy is protected by the fact that, as a general rule, her medical records travel within a defined circle of primary carers.

"Zone two" involves supporting services, and in particular third party payment organisations, which in Australia comprise the Health Insurance Commission (the body administering Medicare), and private health insurance organisations. In "zone two", although the confidentiality of Mrs Drocker's personal data might be preserved through statutory prohibitions on disclosure to third parties, her privacy in the sense of "informational self-determination" is more problematic.

Unless Mrs Drocker has been paying cash for her medical consultations, hospitalisation, diagnostic services and medications without generating any claims for Medicare benefits or reimbursements, a series of medical records by third party

payers would have been created through the medical, hospital, diagnostic and pharmaceutical benefits claims.³² A record is created each time a claim for a Medicare benefit is sent to the Health Insurance Commission (HIC) either by the attending doctor, public or private hospital, diagnostic and pathology laboratory, or by Mrs Drocker.³³ The record contains the patient's Medicare personal identification number, name, date of birth and address, the name of the doctor who had provided the service as well as the date, place and type of the medical service rendered.

Pharmacists claiming benefits under the Pharmaceutical Benefits Scheme (PBS) for dispensing medicines listed in the Schedule of Pharmaceutical Benefits, have to provide the Health Insurance Commission with the name of the patient, the prescribing doctor, the date of service, and the name and dosage of the medicine. All these records can be provided in electronic form.³⁴ The Health Insurance Commission monitors the number of PBS medicines a patient has obtained, and the number of doctor visits at which they were prescribed.³⁵ The prescribing doctors have to inform the Commission about the patient's date of birth, relevant medical history and therapy.

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The electronic Medicare and the PBS pharmaceutical records of a patient have to be kept as separate documents, though they can be stored on the same computer in the Health Insurance Commission's offices. The Commission has the ability to link to Mrs Drocker the personal identification number associated with her Medicare claims information held by the Department of Health and Ageing, Local Government and Community Services. Medicare claims information over five years old is de-identified, but the Health Insurance Commission has the capacity to re-identify the information.³⁶ In the case of Mrs Drocker, the information would include the diagnosis of Kaposi's sarcoma, the Human Herpes Virus 8 infection and the therapy with anti-retroviral drugs. In terms of "the image of her personality" as presented to others through the processing of her personal data, Mrs Drocker would appear to have a condition closely akin to AIDS, with all the negative connotations that attach to this disease.

Mrs Drocker has been undergoing treatment in a private psychiatric hospital. Under the Casemix purchaser-provider system as set out in the National Health Act 1953 (Cth),³⁷ in order to be paid, a private psychiatric hospital must provide the patient's private health insurance fund ("registered health benefits organisation") with data specified in the Hospital Casemix Protocol, which may include information in a patient-identifiable state.³⁸ The data have to be provided about each patient-contributor per episode of care. The information may include clinical notes because, by virtue of s 73BD of the *National Health Act 1953* (Cth), the relevant hospitals are required to provide "all reasonable assistance" to the private health insurance funds to enable the latter "to verify ... the payability of amounts by the organization under the agreement; and the payability of other amounts by the organization relating to professional services rendered in connection with the hospital treatment".

Under the Casemix purchaser-provider system, clinical information about privately insured patients can be disclosed by the relevant hospitals to private insurance funds irrespective of whether the treating physicians are contracted to the funds.³⁹ Neither the hospitals nor the funds need to inform, let alone obtain consent to disclosure from,

doctors or patients-contributors.⁴⁰ Indeed, s 73G(1) of the *National Health Act 1953* (Cth) provides:

No action (whether criminal or civil) lies against a hospital or a day hospital facility, or a person acting on behalf of a hospital or a day hospital facility, for breach of a duty of confidence, or breach of a similar obligation, in relation to the disclosure of information if the disclosure is reasonably necessary in connection with:

- (a) making a payment under an applicable benefits arrangement or assessing whether or not to make such payment; or
- (b) any other matter relating to the operation of an applicable benefits arrangement.

...

(3) This section has effect despite:

- (a) any law (whether written or unwritten) of the Commonwealth, a State or a Territory; and
- (b) any contract, arrangement or understanding;

to the contrary.

The subparagraph (b) is very wide, and clearly envisages secondary uses of the personal information contained in medical records that belong to "zone three".

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In relation to "zone three", Mrs Drocker has neither any right nor any ability to exclude others from accessing her personal information. For example, if Dr GP's clinic is investigated for "inappropriate practice" in relation to Medicare services or prescribing under the Pharmaceutical Benefits Scheme,⁴¹ Pt VAA of the *Health Insurance Act 1973* (Cth) empowers the Director of Professional Services Review or a person nominated by her or him to require the production of clinical or practice records of services rendered or initiated that are relevant to the investigation of Dr GP, or a person employed by him, or a body corporate of which Dr GP is an officer.⁴² The Director or her or his nominee can inspect, retain for a reasonable period, photocopy, or take extracts from these documents.⁴³ The managing director or the nominee can examine all medical records in the practice where Dr GP is employed, without Mrs Drocker being aware of the fact that her personal information is being accessed in this way.

Furthermore, s 8P of the *Health Insurance Commission Act 1973* (Cth) empowers the managing director or a nominee who has reasonable grounds for believing that any of the doctors caring for Mrs Drocker is committing or has committed any offence under the *Health Insurance Act 1973* (Cth), the *Health and Other Services (Compensation) Act 1995* (Cth), the *Medical Indemnity Act 2002* (Cth), the *Crimes Act 1914* (Cth) or the *National Health Act 1953* (Cth),⁴⁴ to require production of the patient's clinical details relating to claims for Medicare or pharmaceutical benefits. If Mrs Drocker has claimed Medicare or pharmaceutical benefits in relation to the treatment of Kaposi's sarcoma, her clinical notes may be produced.⁴⁵ Officers of the HIC are authorised to conduct searches of premises with consent of the occupier (or under warrant in cases of refusal), when to do so is reasonably necessary to ascertain whether "a relevant offence is being committed, or has been committed within the previous 60 days".⁴⁶

However, the power to inspect and copy documents does not extend to those parts of the medical record which contain clinical details relating to a patient. Indeed, where the authorised officer of the HIC has not obtained the consent of the occupier, before issuing an HIC warrant the magistrate must be satisfied that the execution of the warrant will not cause an unreasonable invasion of any patient's privacy.⁴⁷ Following the search, the Commission must advise each patient in writing of what was done in relation to their clinical records, unless to do so would prejudice the investigation.⁴⁸ In other words, the patient has no right to object beforehand to her or his medical records being viewed or used for purposes other than therapeutic care. The HIC can also ask a magistrate for a general enter and search warrant to be executed by police officers, in which case neither the privacy safeguards relating to the seizure of medical records nor the obligation to notify the patient would apply.⁴⁹

Apart from the Health Insurance Commission, most medical disciplinary tribunals and medical practitioners' boards in Australia can either directly, or indirectly through a stipendiary magistrate, issue search warrants and summon production or seizure of books and documents, including clinical notes.⁵⁰ Again, Mrs Drocker may not be aware that her clinical records could be seized, read, photocopied and discussed for reasons that have nothing to do with her medical treatment.

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Less intrusive, but still non-consensual, use of patient-identifiable data relates to research. Thus, under the National Health Regulations 1954 (Cth), Sch 7, Hospital Casemix Protocol,⁵¹ the registered private health insurance funds must provide the Department of Health and the Aged with medical records in respect of every episode of hospital treatment for which a charge is billed to a fund. The information must include: fund/payer identifier; link identifier; provider (hospital) code; the patient's date of birth; postcode; sex; admission date; separation date; mode of separation; and principal diagnosis. This information is to be used for the purposes of modelling, evaluation and research by the Department.⁵² This kind of secondary use of medical records is mandated by statute and consequently beyond the control of Mrs Drocker, or any other patient.

Another statutorily mandated disclosure of health records involves public health reporting. Medical practitioners and hospitals are obligated to report that a patient is unsuitable to be in possession of a firearm,⁵³ notifiable diseases,⁵⁴ prescriptions for Sch 8 drugs (opioids, barbiturates, etc),⁵⁵ tissue samples, such as the blood spots on newborn screening cards, child abuse,⁵⁶ birth certificates (which include information about parents, etc).⁵⁷ Thus Mrs Drocker will be reported to the Anti-Cancer Council of Victoria as suffering from sarcoma.⁵⁸ Her name, address, contact numbers and diagnosis will be placed on a prescribed register. The reports are confidential;⁵⁹ however, they may be accessible to persons studying cancer, providing they comply with NHMRC ethical guidelines. The information acquired by the Council can be released also for the purposes of medical research or the administration of cancer-related public health programs.

Finally, with the narrow statutory exception of "confidential communications" generated in the context of counselling persons who allege that they were victims of sexual offences, which operates in New South Wales,⁶⁰ Victoria⁶¹ and South

Australia,⁶² medical records have to be disclosed in criminal and coronial proceedings. In Victoria,⁶³ Tasmania⁶⁴ and the Northern Territory⁶⁵ doctors are prohibited by statute from disclosing, and cannot be made to disclose, information about patients in most civil proceedings without the consent of the patient. However, the term "proceedings" has been

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interpreted as allowing for pre-trial discovery. A patient's evidentiary privilege does not operate in other jurisdictions, which means that medical records can be disclosed in court without the patient's consent.

To come back to Mrs Drocker: while being treated in the private psychiatric hospital, she writes a long letter to her mother who lives in Queensland. Her mother then reveals that in 1970, while vacationing in Italy, she had a short affair with an Italian man, and Mrs Drocker is not a child of the marriage, but a product of this union. Blood tests confirm the presence of Human Herpes Virus 8 in the mother's blood. The information about her mother is entered by Dr GP and Dr O into their respective records.

Under the privacy legislation, Mrs Drocker has the right to access all of her records with a view to checking and correcting any inaccurate information contained in them. Her concern, however, is the incorrect perception created in the electronic summaries under the control of the Health Insurance Commission, the Anti-Cancer Council and like bodies, that her condition is related to AIDS. If released, either intentionally or negligently, such information might have adverse consequences on Mrs Drocker's career, life insurance policy and social life. Yet there is no inaccurate information in these records. For while Mrs Drocker's treating doctors may amend their records by adding that she is suffering from the endemic rather than epidemic Kaposi's sarcoma, her medical treatment remains the same. The DPL's records will also remain the same, as will the numerous electronic summaries created for the purpose of receiving reimbursement from the Health Insurance Commission and the private health funds. The forms of the HIC are in pdf format and cannot be changed to incorporate such details as the "provenance" of the infection. Perhaps Mrs Drocker could ask that the diagnosis of Kaposi's sarcoma be qualified as "endemic". However, it is doubtful that it would mean much to those who read these records (particularly, in view of the fact that the HHV-8 can be sexually transmitted). The husband halts the divorce proceedings, but the marriage will never be the same, nor will the feeling of privacy and informational self-determination that Mrs Drocker had enjoyed before the fatal diagnosis.

In conclusion, Mrs Docker's personal information has essentially flowed through 14 different transit points of contact.⁶⁶ In this case, each person who collected and managed this information has observed the required standards of confidentiality and non-disclosure. Nevertheless, aware of the number of people and organisations that have accessed her personal health information, Mrs Docker may well feel that her body has been exposed and her privacy shattered. For, despite all the rhetoric about our rights to privacy, in contemporary Australia our right to "informational self-determination" is only open to those who can afford to pay cash for all medical services and medications. The average citizen can only exercise the right to privacy in

the form of "informational self-determination" by not seeking medical advice in the first place.⁶⁷

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- 1 Westin AF, *Computers, Health Records and Citizen Rights* (PBI, New York/Princeton, 1976) p 18.
- 2 See, eg, McMahon M, "The Ritual of Confidentiality" in Freckelton I and Petersen K, *Controversies*
- 3 There is also a definition of "sensitive information", which encompasses information or an opinion about opinions, membership of a political association, religious beliefs or affiliations, philosophical beliefs, membership of a trade union, sexual preferences or practices, criminal record, that is also personal information.
- 4 The Privacy Act 1988 (Cth), s 6, defines "health service" as: "(a) an activity performed in relation to (otherwise) by the individual or the person performing it: (i) to assess, record, maintain or improve the individual's illness or disability; or (iii) to treat the individual's illness or disability or suspected illness or disability or to prepare a medicinal preparation by a pharmacist."
- 5 Excluded, by virtue of s 6(1), from the operation of the Privacy Act are records, which are in the custody of the Archives, are in the open access period, or where the Archives had entered into arrangements with a person other than the individual (under the Act) to provide access to the records for other persons.
- 6 Westin, n 1, p 10.
- 7 For online references to Kaposi's sarcoma, see <http://www.nlm.nih.gov/medlineplus/kaposissarcoma>.
- 8 Plancoulaine S, Abel L and Gessain A, "Epidemiologie du virus herpes humain 8 (HHV-8) ou virus herpes humain 8 (8) Pathol Biol (Paris) 496 (Epidemiology of human herpes virus 8 (HHV-8) or the herpes virus associated with Kaposi's sarcoma)"
- 9 Understanding Kaposi's sarcoma: <http://www.cancerbacup.org.uk/info/kapos/kapos-4.htm>.
- 10 The doctor's doctor, Kaposi's sarcoma at http://www.thedoctorsdoctor.com/diseases/Kaposi_sarcoma
- 11 National Cancer Institute, Division of Clinical Sciences, HIV and AIDS Malignancy Branch: <http://www.dcs.nci.nih.gov/branches/aids/trials/haartks.html>; <http://www.thedoctorsdoctor.com/diseases/hhv8.htm> the Doctor's Doctor, HHV-8: <http://www.thedoctorsdoctor.com/diseases/hhv8.htm>; National Cancer Institute see <http://seer.cancer.gov/publications/raterisk/risks80.html> accessed 6 October 2003.
- 12 Plancoulaine, Abel and Gessain, n 8.
- 13 Sir Nicholas Browne-Wilkinson, in *Stephens v Avery* [1988] 2 All ER 477 at 482, expressed the equivalent way: "Although the relationship between the parties is often important in cases where it is said [sic] that there is a relationship of confidence, the relationship between the parties is not the determining factor. It is the acceptance of the relationship which affects the conscience of the recipient of the information."
- 14 For example, negative injunctions in Leviticus 19.16: "Thou shalt not go ... as a tale-bearer among thy brethren."
- 15 Edelstein L, *Ancient Medicine* (Johns Hopkins University Press, Baltimore, 1987) p 6.
- 16 Mendelson D, "Medical Duty of Confidentiality in the Hippocratic Tradition and Jewish Medical Ethics" *Confidentiality in Australian and Jewish Law* (1997) 12 *Jewish Law Annual* 217; Mendelson D, "Medical Confidentiality" 1 *JLM* 120.
- 17 *Stephens v Avery* [1988] 2 All ER 477 at 482. In *Breen v Williams* (1996) **186 CLR 71**, Gaudron and Gummow J said: "Doctors invariably confide intimate personal details about themselves to their doctors. In some circumstances confidential information may make the relationship between a doctor and patient fiduciary in nature. The doctor is a fiduciary for all purposes. As Mason J pointed out in *Hospital Products Ltd v United States Surgical Corp* in a fiduciary relationship to another for one purpose but not for others."
- 18 *Furniss v Fitchett* [1958] NZLR 396; *W v Egdell* [1989] 2 WLR 689; [1990] 2 WLR 471 at 488-489.
- 19 Medical boards throughout Australia have tended to interpret breach of confidentiality strictly, and require a high standard of proof.
- 20 For example, Health Records (Privacy and Access) Act 1997 (ACT), s 17; Health Act 1993 (ACT), s 17; Adoption Act 1993 (ACT), s 60; Children (Care and Protection) Act 1987 (NSW), s 106; Disability Services Act 1982 (NSW), s 22; Human Tissue Act 1983 (NSW), s 37; Medical Practice Act 1992 (NSW), ss 10-12.

(NSW), s 72; Health Practitioners and Allied Professionals Registration Act 1996 (NT), s 68; Health 97; Medical Act 1993 (NT), s 13; Human Tissue Transplant Act 1979 (NT), s 28; Adoption of Children Act 1991 (Qld), s 141; Mental Health Act 2000 (Qld), s 426; Health Act 1937 (Qld), s 100I; Workplace Health and Safety Act 1989 (Qld), s 49; Transplantation and Anatomy Act 1979 (Qld), s 49; Health Services Act 1988 (SA), s 36; South Australian Health Commission Act 1976 (SA), s 64; Public and Environmental Health Act 1983 (SA), s 39; Guardianship and Administration Act 1995 (Tas), s 86; Health Complaints Act 1995 (Tas), s 49; Public Health Act 1997 (Tas), s 62; Human Tissue Act 1985 (Tas), s 31; Mental Health Act 1996 (Tas), s 49; Cancer Act 1958 (Vic), s 61; Health Services Act 1988 (Vic), s 141; Health Services (Governance) Act 1988 (Vic), ss 89, 90; Adoption Act 1984 (Vic), s 89; Adoption Act 1994 (WA), s 127; Young Offenders Act 1997 (WA), s 127; Mental Health Act 1996 (WA), s 206; Medical Act 1894 (WA), s 9; Royal Commission (Custody of Children) Act 1982 (WA), s 34.

- [21](#) The duty extends to such transient relationships as when the person comes to the doctor for a single visit.
- [22](#) Ortiz DR, "Privacy, Autonomy and Consent" (1989) 12 Harv JL & Pub Pol'y 91 at 91-92.
- [23](#) Thus there is no express right to privacy in the United States Constitution, though the United States Supreme Court has recognized a constitutional right to privacy, and applied it in such diverse areas as child rearing and education (see *Griswold v Connecticut* 381 US 479 (1965); *Roe v Wade* 410 US 113 (1973); *Planned Parenthood v Casey* 505 US 824 (1992)); family relationships (*Prince v Massachusetts* 321 US 158 (1944)); procreation (*Skinner v Oklahoma* 316 US 545 (1942); *Roe v Wade* 410 US 113 (1973); *Planned Parenthood v Casey* 505 US 824 (1992)); marriage (*Loving v Virginia* 388 US 1 (1967)); contracts (*Eisenstadt v Baird* 405 US 438 (1972)); and the right of a woman to decide whether or not to abort (*Roe v Wade* 410 US 113 (1973); see also *Roe v Wade* 410 US 113 (1973)). Also see Buchanan GS, "The Right to Privacy" (1890) 4 Harv L Rev 193.
- [24](#) Until the 19th century, privacy as a social and legal construct was nebulous. Social, economic and legal conditions were different for the rural and urban poor, whereas royalty and the nobility, for dynastic reasons, chose not to avail themselves of the law.
- [25](#) Hughes G, Data Protection in Australia (The Law Book Co Ltd, Sydney, 1991) p 1.
- [26](#) Westin AF, Privacy and Freedom (Atheneum, New York, 1967) p 25.
- [27](#) German Federal Administrative Court (Bundesverfassungsgericht) (BeverfG, EUGRZ, 1983) p 588, and the Internet: An Analysis of the European Community's Privacy Legislation in the Context of the World Trade Organization.
- [28](#) The long title of the Privacy Act 1988 (Cth) reads: "An Act to make provision to protect the privacy of personal information; and (b) providing an accessible framework for the resolution of complaints regarding the Health Records and Information Privacy Act 2002 (NSW) is expressed in similar terms, though its object is to protect the privacy of health information with the public interest in the legitimate use of that information, and about their health care, and (c) to promote the provision of quality health services."
- [29](#) In [Breen v Williams](#) (1996) [186 CLR 71](#), the High Court determined that the records created in the course of a visit to a medical practitioner or the health care facility which created them, and, in absence of specific legislation, were the property of the practitioner or the facility to whom they were sent. However, under the Privacy Act 1988 (Cth), the Health Records (Privacy and Access) Act 1988 (Cth) and the Health Records and Information Privacy Act 2002 (NSW), patients have a legally enforceable right to access their records from clinics, hospitals, nursing homes and diagnostic services providers. The legislation schemes impose a duty on the provider to provide access to the records.
- [30](#) In those jurisdictions, where the statutory regime is stricter, the State or Territory rules may prevail.
- [31](#) The term "personal data" has been defined in the European Union Directive (95/46/EC) as "any information relating to an identified or identifiable natural person; the identification may be by reference to an identification number or to one or more factors specific to his physical, physiological, mental, economic, cultural, social or other characteristics." See *Bergkamp and Dhont*, n 23. The Directive defines an "identifiable person" as "one who can be identified either directly or indirectly, by reference to an identification number or to one or more factors specific to his physical, physiological, mental, economic, cultural, social or other characteristics."
- [32](#) See ss 20(1), 20(2) and 20A of the Health Insurance Act 1973 (Cth).
- [33](#) Similar records are created and owned by private health insurance funds.
- [34](#) Electronic communication between the medical practitioner and the Health Insurance Commission (HIC) is required for applications for authorisation to exceed the maximum quantity in one prescription for a pharmaceutical product.

- [59](#) Cancer Act 1958 (Vic), s 61.
- [60](#) Evidence Act 1995 (NSW), ss 126A – 126J.
- [61](#) Evidence Act 1958 (Vic), ss 32B – 32G.
- [62](#) Evidence Act (Confidential Communications) Amendment Act 1999 (SA) incorporated into Evidence Act 1958 (Vic), s 28(2).
- [63](#) Evidence Act 1958 (Vic), s 28(2).
- [64](#) Evidence Act 1910 (Tas), s 96(2) and s 96(2A).
- [65](#) Evidence Act 1996 (NT), s 12(2).
- [66](#) Each of these "transit points" in the flow of her medical records is vulnerable to misuse, for example confidentiality, or by conversion of the information contained in the record by third parties.
- [67](#) A Symposium on Legal and Ethical Issues Relating to Electronic Health Records will take place in Melbourne. See *Journal of Law, Medicine & Ethics* for further details.
- * Based on a keynote presentation delivered at the 24th Annual Conference of the Health Information Management Society of Australia, "The Medical Record: Issues of Confidentiality and Privacy", 8-10 August 2003, Sydney. Acknowledgement to the Australian Research Council Grant, 2002-2004 (Administering Institution: Deakin University; Chief Investigators: Associate Professor John Paterson, Deakin University; Dr Livia Iacovino, School of Information Management and Systems, Monash University; and John Paterson, Faculty of Law, Monash University. The author also wishes to thank Ramanan Rajendran for his assistance in the preparation of this paper.