

Lecture Notes, 2009-2010 (Code: 03.02-v2a-12.09)

Medical Law

Topic 3 (of 10), **Lecture 2** (of 2):

Permanent Recordings of Patients' Confidences and Patients' 'Rights' of Access to 'Their' Medical Records

Aim:

To review the legal and ethical considerations which determine whether a patient has access to 'his' medical records.

Objectives:

After careful study of this topic you should be able to:

1. Explain, with reference to particular situations, who owns a patient's records;
2. Explain the relevant statutory provisions of: the DPA 1998; the Access to Medical Records Act 1988; Access to Health Records Act 1990 [largely repealed]; and the Senior Courts Act 1981 in relation to the disclosure of, or use in evidence of, a patient's medical records;
3. Outline how, if at all, a patient may secure access to his records.

Ownership of and Access to Medical Records

If an autonomous patient owned his medical records then he could have possession of them and, via the principle of confidentiality, he could disclose, or refrain from disclosing, or control the disclosure of, information contained in them. However, as noted by *Schoenberg* and *Safran*¹:

“Many hospitals consider the records in their systems to be their property, whereas many patients argue that their medical information is their own. Consequently, a distinction is made between ownership of the physical record and the right to access (or duplicate) data that are stored in it. Policies on this issue differ substantially between delivery networks, [American] states, and countries.”

This echoes the view of *Kennedy & Grubb* (*Medical Law Text With Materials*), who expressed the opinion that, in relation to access to medical records: “In our view, this *prima facie* turns on who owns the paper being used”.

Quite simply, then, *in whom is the ownership of a medical record vested?*

(I) Private patient

1. *Paper belonging to the clinic, hospital or other institution*

Even if a patient contracts with a doctor the issue of who owns the document(s) depends on

¹ *BMJ* 2000; 321: 1199-1203 (11 November)

the contract made (if any) between the doctor and *the institution*. In the absence of any specific agreement the ownership of the document(s) in question vests with the clinic or other institution. Where a patient contracts directly with the clinic or other institution ownership of the document(s) would presumably vest with the clinic, etc, unless otherwise agreed.

(N.B.: X-ray films and prints

The contentious point here, if there is one, is whether a private patient pays for the film or for the expert interpretation of the film. Many hospitals, when issuing an X-ray report to an outside doctor, have printed on the report a standard form of wording that such a report is not to be used in connection with litigation. The legal effect of this is uncertain. All that is known is that disclosure of x-rays as part of the disclosure of medical records does not incur an extra charge under the *Data Protection Act 1998*).

2. *Paper belonging to the doctor*

In this instance, in the absence of a particular agreement to the contrary, the document probably belongs to the doctor, irrespective of whether the patient contracted with the doctor or the clinic, etc.

(II) NHS patient

1. *The general practitioner*

Medical records made by GPs are ‘... made on forms ... supplied by the [Health Authority for the patient in question] and stated expressly to remain their property’ (per *Brazier, Medicine, Patients & the Law*, 2/e. p46) {But see, now: *s.7 Data Protection Act 1998*}.

2. *Hospital doctor*

Such records are made ‘on NHS property’ (per *Brazier*) [‘property’ referring to the Health Authority’s ownership of the paper] and so ‘clearly belong to the relevant Health Authority’ (per *Kennedy & Grubb*.)

In outline, then, a patient has no legal right of access to ‘his’ medical records if he has no ownership rights in them. Accordingly, *MacLean and Maher* say this shows that ‘... the rules on access to medical records adopt the doctor’s rather than the patient’s perspective on confidentiality’. However, in line with the views already expressed, the authors point out that what is more important is the ‘distinction ... between the medical records as mere physical objects (which will generally belong to the doctor making them or, in most cases in the UK, to the NHS) and *the information contained in them* ... [the question then being:] to whom does the property right in the *information* (rather than the documents) belong?’ Again, if the doctor’s perspective is taken then: ‘... the doctor retains his right to the information as resulting from the process of professional decision-making from which it originated. [On the other hand] the law appear[s] to adopt the patient’s perspective on confidentiality in justifying rules on discovery or recovery of documents’. [see p6]

While *Kennedy and Grubb* state that: ‘Generally, the common law has *not* recognised a right in the patient to have access to the information in medical records about himself’, they note a particular exception based on the dictum in *C v C* (1946):

C v C [1946] 1 All ER 562

Here, *Lewis J* said the question to be answered was:

“Is a doctor, when asked by a patient to give him or her particulars of his or her condition and illness to be used in a court of law, when those particulars are vital to the success or failure of the case, entitled to refuse and in effect to say: ‘Go on with your case in the dark and I will tell you in court when I am subpoenaed what my conclusions are?’ ...

“... It is, of course, of the greatest importance ... that proper secrecy should be observed in connection with ... the confidential relationship existing between doctor and patient. But, in my opinion, those considerations *do not* justify a doctor in refusing to divulge confidential information to a patient or to any named person or persons when asked by the patient so to do. ... and in *all cases* where the circumstances are similar the doctor is not guilty of any breach of confidence in giving the information asked for.”

Apart from cases where litigation is pending, if a health care professional has been negligent in the administration of treatment, *Donaldson MR* is of the opinion that if a patient asks what went wrong then: “... in medical negligence cases, there is a duty of candour resting on the professional man ...”. This also appears to be recognised by the Medical Defence Union, whose view is that ‘the patient is entitled to a prompt, *sympathetic* and above all truthful account of what has occurred’ (As stated in: *Naylor v Preston Health Authority* (1987)). So, while *Donaldson MR* sought, *obiter*, to put a duty of care on disclosure of treatment *received* on a par with the affirmation in *Sidaway* that a doctor was under a duty to answer his patient’s questions as to the treatment *proposed*, *Sidaway* was subject to clinical judgment whereas the duty of disclosure in respect of treatment *received* doesn’t carry this qualification and so would appear to be a strict duty should it ever become the ratio of a case.

[N.B.: That a patient does not have a common law right to seek disclosure of his medical records was affirmed in: *R v Mid Glamorgan FHS, ex p Martin*, [1995] 1 All ER 356 (CA). Moreover, non-disclosure did not infringe his human rights.]

Statutory Provisions Relating to Confidentiality and Access to Information

(1) Storage of Personal Data on Computers: Elements of the Data Protection Act 1998 (DPA 1998)

The *DPA 1998*, which implements the *EC Data Protection Directive, 95/46/EC*, on the ‘*Protection of Individuals with Regard to the Processing of Personal Data and on the Free Movement of Such Data*’, aims to regulate who may hold information; the purpose for which it may be held or collected; who may have access to it and; its accuracy.

In *s.1(1)* of the 1998 Act, ‘Data’ means information which [*inter alia*] –

(a) is being processed by means of equipment operating automatically in response to

- instructions given for that purpose, [and]
- (b) is recorded with the intention that it should be processed by means of such equipment recorded in a form in which it can be processed by equipment operating automatically in response to instructions given for that purpose’.

The eight principles of data protection are set out in *Schedule 1 of the DPA 1998* include:

- (a) Information must be obtained and processed fairly and lawfully.
- (b) The purposes for which the information is held must be specified, and must be lawful.
- (c) Personal data shall be *adequate, relevant* and not excessive in relation to the purposes for which they are processed.
- (d) Personal data must be accurate and, where necessary, kept up to date.
- (e) Personal data must not be held for longer than is necessary.
- (f) Personal data shall be processed in accordance with the rights of data subjects under this Act.

The principal provisions of the **DPA 1998** affecting the NHS and individuals are those between *ss.7-14, viz;*

s.7(1)(c) DPA 1998 says that the individual has a right to have communicated to him in an intelligible form information constituting any personal data of which that individual is the data subject; and this is subject to making a written request and payment of a regulated fee: *s.7(2)*. {**N.B.:** Provisions supplementary to *s.7* are provided for in *s.8*}

(However, this *prima facie* right to access all records – manual or computerized – as provided for in *s.7*, is subject to the Secretary of State’s power in *s.30(1)* to exempt or modify a patient’s access to records – see: *SI 2000/413, infra*. If the patient is to be denied access, the decision is made only after consulting the health professionals responsible for the patient’s care. An aggrieved patient has the right of appeal to the Information Commissioner’s Office)).

ss.10 & 13 DPA 1998 provide for compensation for inaccurate information if damage, distress or loss is suffered: and for unauthorised disclosure.

s.14 provides that the courts have powers to order rectification and erasure of data

[**NB.:** The *Data Protection Act 1998* repealed the 1984 Data Protection Act as from March 1st 2000. From that date, it has applied to ‘all paper and computer records whenever created.’ Moreover, it repealed the *Access to Health Records Act 1990, infra*, except to the extent that the 1990 Act applies to deceased patients].

Limitations on Access

If access to the data would be likely to cause harm to the data subject (‘the patient’) *or any other person*, access may be denied under the provisions of the *Data Protection (Subject Access Modification) (Health) Order 2000, SI 2000/413*.

Corporate responsibility of NHS bodies to protect data

Responsibility for the protection of a patient’s data is not confined to health professionals: the employing body also has a responsibility as the data controller – a ‘*Caldicott guardian*’ – named after the author of the Report (*Dame Fiona Caldicott*) that detailed six ‘Caldicott principles (that are additional to the eight principles of data protection) – the *Six Caldicott Principles* being:

- The use or transfer of information should be justified;
- Patient information should not be used unless it is absolutely necessary;
- Use the minimum necessary patient information;
- Access to patient information should be on a strict ‘need to know’ basis;
- All staff must be aware of their responsibilities;
- All staff must understand and comply with the law.

(2) The Access to Medical Reports Act 1988

This Act came into force on January 1st 1989 and applies to both private and NHS patients. It does *not* give a patient a *general right to access* to medical records but provides that in certain circumstances (s)he has a right of access to an individual medical report sought from a particular doctor in connection with *employment* or *insurance* purposes. If that doctor does *not* have ‘responsibility for the clinical care of the individual’ (s.2(I)) because he is not the individual’s GP, then the provisions of the Act *do not* apply.

In outline:

A potential employer or insurance company seeking a medical report on an individual must obtain that individual’s consent to seek the report: i.e. the patient has some control over the dissemination of information on his medical records; s.3(I) As a condition to granting consent the individual may require that he be given access to the medical report prior to its supply to the employer/insurance company: s.4(I). (Where this condition has not been imposed the individual still has potential right of access up to six months thereafter: s.5)

‘Access’ means inspection of a copy of the medical report or obtaining such a copy: s.6(4) & (3). In the latter case, the individual may be charged a reasonable fee: ss.4(4) & 6(3).

NB: (1) *The Individual’s right of access is not absolute.* s.7 provides for three situations where a doctor will be excused from granting access, viz;

- (i) where, in the doctor’s opinion, disclosure would be ‘likely to cause serious harm to the physical or mental health of the individual *or others*’;
- (ii) where disclosure would indicate the intentions of the doctor in respect of the individual; and
- (iii) where disclosure would be likely to reveal information about another or identify another who had supplied information to the doctor unless that other had consented or was a doctor in whose care the individual had been.

Each of the above situations may prevent the individual from obtaining access to the whole or part of the medical record.

- (2) If a doctor wishes to deny access to the whole of a report then he *cannot* supply that report to the potential employer or insurance company without the individual’s consent.

It is usual practice to send extracts or copies of notes to doctors outside the hospital service for bona fide use in treatment but not for purposes connected with litigation. (As previously noted, ‘Information shared with other doctors, nurses or health professionals participating in caring for a patient’ is regarded as a permissible breach of confidence by the GMC.)

(3) Access To Health Records Act 1990

The *Access To Health Records Act 1990* [as now largely repealed by the *Data Protection Act 1998*] received the Royal Assent on 13 July 1990 and it came into force on November 1 1991. The Act offered access to medical records compiled from this date onwards: it did not have retrospective effect nor was there a common law right to access records compiled before this date: *R v. Mid Glamorgan FHSA, ex p Martin*, [1995] 1 All ER 356 (CA).

The 1990 Act that was brought into force following the decision of the *European Court of Human Rights* in *Gaskin v UK* (1989). Amongst its provisions was the intention to establish a right of access to health records by patients and other persons. However, the only remaining practical significance of this Act is in relation to the records of *deceased* persons, given that the *DPA 1998* relates only to information about living persons. That is, the essence of the 1990 Act is now confined to the provision of access to the records by the personal representative of the deceased person or any other person who may have a claim that has resulted from the patient's death – the proviso being that in respect of a person having a claim, access is restricted to the relevant information, only.

The provisions of the 1990 Act included:

s.1 providing that a '*health record*' is any information (including an expression of opinion about the patient) made by or on behalf of a health professional relating to the physical or mental health of an individual who can be identified from that information, or from that and other information in the possession of the record holder. A 'record holder' will include the patient's GP ...

s.2 gave '*health professional*' the same meaning as that in the *Data Protection Act 1998* – and so includes: a registered medical practitioner; a registered dentist; a registered optician; a registered nurse, midwife or health visitor; and a music therapist employed by a health service body.

s.3 contained the main provisions of the Act: it specified who had the right of access to health records and that an explanation of terms which were not intelligible without explanation had to be provided with the record. A written application to the record holder was to be made by the patient; a person, authorised in writing, on the patient's behalf; parents or guardians of children (under 16 years); court appointees; and in the case of deceased patient's, the personal representatives and any person who might have a claim arising out of the death.

s.4 provided that a right of access could be wholly excluded, for example, in applications by or on behalf of children or deceased patients. Access to information may be denied if it would, in the opinion of the record holder, disclose information provided by the patient in the expectation that it would not be disclosed to the applicant.

s.5 provided for access to any part of a record to be denied where, *inter alia*, in the opinion of the record holder, it would disclose (i) information 'likely to cause serious harm to the physical or mental health' of the patient or of any other individual, or (ii) information relating to or provided by an individual (other than the patient or the health care professional involved) who could be identified from that information (unless that individual consents).

(4) Freedom of Information Act 2000

There is a popular misconception relating to this Act that came into force in January 2005. Whereas the Act gives a general right of access to information held by public authorities, it is subject to significant exceptions so far as a patient trying to access his medical records is concerned. Suffice it to say that s.40 of the Act provides that:

Any information to which a request for information relates is *exempt information* if it constitutes personal data of which the applicant is the data subject.

The outcome is that a patient (a data subject) requiring access to personal information should pursue the provisions of the *Data Protection Act 1998*. In essence, the Freedom of Information Act 2000 is of no use to a patient wishing to gain access to his medical records as it aims to avoid overlapping the provisions of the 1998 Act.

A Modern Trend Towards Relaxation of Restrictions of Patient Access to Medical Records?

An erosion of the restriction on patient access to information seems to be taking place both by way of statutory and non-statutory sources. First, *Art.8 ECHR*, as given the force of law by the *Human Rights Act 1998*, has been interpreted² as providing a *prima facie* entitlement to a patient to access his records: *MG v. United Kingdom* [2002] 3 FCR 413; and to be a ‘part of the State’s obligation to respect the private and family life of its citizens’³. In common with provisions of the Data Protection Act 1998, however, it must be noted that it is a *prima facie* right, not an absolute right.

Secondly, in *paragraph 7* of the *GMC* publication ‘*Confidentiality: Protecting and Providing Information*’ (2004), the GMC asserts that: ‘Patients ... have a right to information about any condition or disease from which they are suffering’. Whilst the status of this publication constitutes no more than ‘guidance’ (para.2), its influence should not be underestimated.

Thirdly, at common law, the impact of *Lord Woolf’s* dictum in *Pearce v. United Bristol Healthcare NHS Trust* (1991) that disclosure of information should apply to any ‘significant risk which would affect the judgment of a reasonable patient’ is still to be determined.

The evident uncertainty that these provisions and decisions will have on aiding a patient gain access to his records can be seen in the statement of *Brazier* who can do no more than express the hope that:

With luck the Data Protection Act will provide a legal framework within which a culture of openness will flourish. Fears that such a culture will result in patients being forced to cope with unwanted information are misplaced. No one is obliged to seek access to his records⁴.

² By the *European Court of Human Rights*

³ per *Mason & Laurie*, *Mason & McCall Smith’s Law and Medical Ethics*, 7/e, 2005, p287.

⁴ *Brazier*, *Medicine, Patients and the Law*, 3/e, 2003, p78

(5) The Use of Medical Records in Litigation: Discovery of Medical Records

If a patient believes he has a claim in respect of negligence then, in order for his legal advisers to make an informed opinion, access to the patients notes, etc, would be of clear benefit. That he has no such right of access - because ownership of the records does not vest in him - was noted above. Nevertheless, the law has evolved to the benefit of the patient as outlined below:

In 1959 the Ministry of Health sent a circular to all hospitals advising them that they should reveal all information to solicitors acting on behalf of patients who were bringing action against a hospital *unless* there was a good reason for non-disclosure. Unfortunately, a good reason cited for non-disclosure included the fact that the claim had no justification or no apparent justification and that *disclosure could have a bearing on the defence*: HM(59)88. A frequent result was that this was interpreted as a justification for refusing disclosure.

Legislation giving the courts power to compel access to documents was enacted in 1970, viz. the Administration of Justice Act 1970. *s.31 AJA 1970* gave the Courts ‘ ... power to order a person who appears to be likely to be a party to the proceedings and to be likely to have in his possession, custody or power any documents which are relevant to an issue or likely to arise out of that claim:

- (a) to disclose whether those documents are in his possession, custody or power, or
- (b) to produce to the applicant such of those documents are in his possession, custody or power.’

Additionally, *s.32* gave power to the proposed plaintiff to apply to the Court to obtain records in personal injury cases prior to actions from persons who are *and/or are not likely* to be parties to the action. This meant that (say) if a patient had started proceedings against a doctor but believed that a hospital authority or clinic held notes of value to his claim, then the authority or clinic could be made to hand over the notes.

The AJA 1970 was replaced by the *Supreme Court Act 1981* [now renamed *Senior Courts Act 1981*] and the substance of ss.31 & 32 of the 1970 Act is now to be found in *ss.33 & 34 of the 1981 Act* (in accordance with rules of court under the *Civil Procedure Act 1997, s.8* {see the Civil Procedure Rules, Rules 31.7 and 31.16}).

Whereas in *MacIvor v Southern Health Board* (1978) the House of Lords formed the opinion that under the 1970 Act *the patient himself* was entitled to see any documents disclosed, the 1981 Act is less favourable to patients in that a Court may limit disclosure to:

- (i) the patient’s legal advisers; or
- (ii) the patient’s legal and medical advisers; or
- (iii) if the patient has no legal adviser, to his ‘medical or other professional adviser’.

It is up to the Court to decide whether a plaintiff/patient sees the records.

Brazier (*Medicine, Patients and the Law*, 3/e, pp185-186) notes three final matters relating to disclosure:

- (1) The intention to bring proceedings and the likelihood that they will go ahead must be real before the Court will order disclosure. The patient ... “cannot use an application for disclosure to mount a ‘fishing expedition’ on the off-chance that some evidence of negligence will come to light”.
- (2) It is not clear whether a patient would be able to see any notes of any inquiry ordered by a health authority in relation to his misadventure;
- (3) The Courts have power to refuse disclosure where to do so would be injurious to the public interest - a most unlikely situation if all that is requested is the patient’s own medical notes.

Present/Future Developments

Under a strategy contained in Information for Health, and Information Strategy for the Modern NHS 1995-2005, there has been an increase in electronically stored and disseminated patient records (Electronic Patient Health Records – ePHRs) via an NHS network. This will be aided by the development of ‘smart card’ patient records where the information will be stored on something akin to a credit card which patients will be able to carry with them. Overall, greater emphasis is being given to security and to the non-disclosure of information to those not having a legitimate interest in it.

References

- Brazier, M and Cave E.** *Medicine, Patients and the Law* 4/e, 2007. London: Penguin, Ch.4;
- Mason & Laurie.** *Mason & McCall Smith’s Law and Medical Ethics*, 7/e, 2005 Oxford: OUP Ch.8 (pp286-294);
- Herring, J.** *Medical Law and Ethics*. Oxford: OUP, 2008. Ch.4 (pp197-204 and 215-236);
- Stauch, Wheat & Tingle.** *Text, Cases & Materials on Medical Law*, 3/e, Abingdon: Routledge-Cavendish, 2006. Ch.5 (pp264-275).
- Data Protection Act 1998**

Past Paper / Potential Examination Questions

1. How, if at all, do the circumstances in which a patient has a right of access to his health care information provide a justifiable contrast with the circumstances under which access is denied?
2. The evolution of statutory enactments relating to the disclosure to patients of their medical records has represented a welcome development in recognising, and giving primacy to, patient autonomy.

Discuss.