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ACCESS TO HEALTH RECORDS ACT 1990

The Concerns of Community Health Councils

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30 Drayton Park London N5 1PB Tel: 071 609 8405 Fax: 071 700 1152

ACCESS TO HEALTH RECORDS ACT 1990 - THE CONCERNS OF COMMUNITY HEALTH COUNCILS

By statute, and under the Patient's Charter, all citizens have the right to have access to their health records. This is essential for patients considering whether to make a complaint or pursue legal redress against the NHS. In any case, there is no good reason in general for information about patients to be kept from them and access allows patients to note errors in their records. The 1990 Act was also necessary to bring written material broadly in line with computerised information which is covered by the Data Protection Act.

Community Health Councils have wide experience of the operation of the Health Records Act. Following issues raised by individual CHCs, the Association of Community Health Councils for England and Wales conducted a survey of its members to identify the main difficulties and the findings are reported below. Some of the Act's limitations follow directly from the provisions of the Act and the Guide issued by the NHS Management Executive. Other problems do not follow automatically from the Act but may require new guidance or legislation to resolve.

Legal Restrictions

Despite the unconditional statement in the Patient's Charter of the existing right "to have access to your health records", a number of important restrictions to that right are laid down in the Act. To quote the Guide (p10):

> Section 5(1) sets out three cases where access is not to be given to the whole of a health record.
>
> The first is the case where, in the opinion of the holder of the record, giving access would disclose information likely to cause serious harm to the physical or mental health of the patient or of any other individual.
>
> The second is where giving access would, in the opinion of the holder of the record, disclose information relating to or provided by an individual other than the patient who could be identified from that information.
>
> The third is where the relevant part of a health record was made before the commencement of the Act on 1 November 1991.

In addition, access is not given "if the record includes a note, made at the patient's request, that he (sic) did not wish access to be given on such an application" (section 4(3)). Access is not given to children "unless the holder of the record is satisfied that the patient is capable of understanding the nature of the application" (section 4(1)). Nor is access given to someone having parental responsibility unless the child concerned has consented or, where the child is "incapable of understanding the nature of the application", giving access is in the child's "best interests" (section 4(2)). It should also be noted that under Statutory Instrument 746 of 1993 access is not given to "any part of a health record which would disclose information showing that an identifiable individual was, or may have been, born in consequence of treatment services within the meaning of the Human Fertilisation and Embryology Act 1990".

However, the NHSME Guide states that: "as a matter of principle, patients should be allowed to see what has been written about them". The Guide supports "informal, voluntary arrangements" which "would be in keeping with the underlying principle of greater access to personal health information" (p2). Furthermore: "It is anticipated that in most cases a patient will orally request access to the records in the course of treatment, and that the health professional responsible for that

episode of treatment may wish to hand the record to the patient for inspection or go through it with him. Such a request will not constitute an application under the Act" (p9). The Act defines "application" as "an application in writing" (section 11) so if a patient wishes to request access without formally "applying", s/he could be advised to do so "orally".

In relation to formal applications under the Act, there is no right of access to records made before November 1991 even where a health episode started before then and ended afterwards - unless access to the earlier information is necessary "to make intelligible any part of the record" made after November 1991 (section 5(2)). For example, one CHC reports: "One complaint dealt with a pregnancy & the crucial events happened in October 1991 & we had problems getting hold of the records pre November (the baby was due in January 1992)". Another CHC argues: "The law is sometimes interpreted as meaning that access cannot be given to such records, whereas it simply gives discretion to the record holder".

According to one CHC: "The implementation of the clause stating that information can be withheld when the record holder believes that access is likely to cause the patient or another person serious physical or mental harm is extremely variable". Where information is being withheld, the NHSME Guide suggests that "the holder may not wish to volunteer the fact" to the patient: "If confronted with a direct request as to whether access has been given to the whole of the record a holder is entitled to respond that the requirements under the Act as to access have been fully complied with..." (p21). As a CHC comments: "The Department of Health advice to record holders - to say that they have acted in accordance with the Act - is clearly inappropriate and can serve only to create suspicion".

Paragraph 10 of page 20 of the Guide may mislead. It lists three issues on which the health professional concerned should advise the record holder and this list includes "whether access would be in accord with the best interests or wishes of the patient". However, under section 4 of the Act, consideration of the patient's "best interests" applies only to children (or pupils in Scotland) and not to adult patients. After listing the three issues for advice, the Guide states: "These are the only circumstances in which access may be limited or excluded". However, the Guide then goes on to refer to records made before 1 November 1991 which are also excluded in normal circumstances.

Who has Access

Where a patient has died, access is available to the patient's "personal representative" but this phrase is not defined. It may be assumed that the patient's next of kin will be a "personal representative" but even this is not crystal clear, according to one CHC: "Some interpretations essentially deny access even to next of kin, others provide reasonably free access. This needs to be clarified". Another CHC's Chief Officer reports:

> "I have been contacted by the father of a young man who was killed in a road accident and who was a psychiatric patient for some years. The father would like to obtain copies of his son's medical records because he has a fear that his son should have been receiving more help as a psychiatric patient than he appeared to be. He has applied to various hospitals for copies of his son's records but has been asked to provide evidence that he is his son's personal representative. However, no one seems to know what evidence he needs to produce."

Access to "personal representatives" is "subject to the recorded wishes of the deceased patient" (p19). It is not clear whether that means the representative has access unless the patient's wishes to the contrary have been recorded or whether it means that the representative has access only when the patient has positively

expressly recorded his/her wish that access should be made. Section 4(3) states that access shall not be given where the record of a patient who has since died "includes a note, made at the patient's request, that he did not wish access to be given on such an application". This may be taken to imply that in other circumstances access should be allowed.

However, section 3(1) states that an application for access can be made by "a person authorised in writing to make the application on the patient's behalf". Also, the Model Form (Appendix 1 to the Guide) includes the statement: "I am the deceased patient's personal representative and attach confirmation of my appointment" (p18). If it is required that the deceased patient has recorded his/her wish that access be made, and that the representative has been given a document confirming appointment, then the next of kin may find it difficult to gain access when the patient has died quickly or become comatose before dying. Clearly this could be important if the family feels that the patient's death may have been due to the behaviour of the doctor.

In addition to the "personal representative" of a dead patient, applications can also be made by "any person who may have a claim arising out of the patient's death" (section 3(1)). Access is not given to "information which is not relevant to any claim which may arise out of the patient's death" (section 5(4)).

People authorised in writing can apply for access in relation to the records of patients who are living. In relation to access by relatives and others to records held by large providers, one CHC reports: "The onus is on the applicant to prove they have a right to access. There is a special problem for patients' mental health records".

What Records Include

To quote the Guide: "The Act defines a 'health record' in Section 1(1) as meaning a record which consists of information 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 holder of the record, and which has been made by or on behalf of a health professional in connection with the care of that individual" (p6). Correspondence between GPs and consultants should for example be seen as "health records" and so should X-rays. It may be important to check that all records are made available, including nursing records.

The definition of a "health record" has been raised in relation to Independent Professional Review. This is the third and final stage of the complaints procedure in relation to clinical practice at a hospital. At the first stage, the designated Complaints Officer will usually arrange a meeting between the complainant and respondent (normally a consultant). The second stage involves an examination of the complaint by the Regional Medical Officer in order to decide whether it is appropriate to proceed to the final stage. At the Independent Professional Review stage of the hospital complaints procedure, there is a meeting of two consultants not involved in the patient's treatment which includes a discussion with the patient or about the patient's condition and may include a physical examination.

However, there is no obligation under the procedure to make a full report of the consultants' findings available to the complainant. In response to ACHCEW, the Department of Health argues that this report is not a "health record": "Section 1 of the Act defines a 'health record' as a record made by a health professional in connection with the care of an individual. Clearly, a stage 3 report is drawn up not for patient care but in respect of a complaint. In addition, the report of the Independent Professional Review may well cover much wider issues than the patient's health which would make it inappropriate for it to be released to that patient". However, it could be argued that complaints procedures are "in connection with the care" of the patient; and that there is no provision in the Act

for denying access to a record on the ground that it "may well cover much wider issues".

The reference in the definition to the record being "in connection with the care" of a patient may also be used to deny patients access to correspondence between a GP and other bodies such as Social Security offices or housing departments. If this restricted reading of the Act is legitimate, it will need to be amended to allow full access by citizens to crucial information about them, sometimes inaccurate, misleading or irrelevant, which is being passed from health professionals to other bodies. Access to reports by doctors made for employment or insurance purposes is governed by the Access to Medical Reports Act of 1988.

It is important that correspondence from patients is not automatically placed with their health records. For example, it should not be possible for one doctor to learn from looking through health records about grievances which patients may have had against other doctors. Similarly, the NHSME Guide states: "Following conclusion of the inspection the application form should be noted and attached to the record" (p21). This instruction is open to question. To quote the Patient's Charter: "some people have told us that they fear a 'come-back'; they worry that if they tell a doctor or hospital their real views they will be labelled as 'awkward'." Similarly, doctors may regard patients as likely to be "awkward" simply because they are known to have inspected their health record in the past.

Role of the "Health Professional"

The doctor concerned plays a major role in the decisions on (a) whether to allow access; (b) if so, whether it should be to the full health record or only to an extract; and (c) if so, whether the doctor concerned should be present when the health record is being inspected. These decisions are made by the "holder" of the health record who, for general practice records, is the patient's GP.

For hospital records, the "holder" is obliged to take advice on these issues from the "appropriate health professional" ie the doctor who had "clinical responsibility for the particular episode of treatment" (p20). This may give doctors scope for obstructing patients from collecting evidence with a view to making a complaint. In practice, as one CHC reports: "Many record holders and administrators do not understand that only the record holder has the power to make decisions on access to records. That is, some believe that they can only give access to records made by others with their permission. In fact, they need only seek their advice and then take this into account when making a decision in line with the Act."

Similarly, an applicant received a letter from a Trust's Medical Records Manager saying that he, the Manager, had "applied" to the relevant health professional "for consent to copy your Casenotes". Record holders in fact are quite entitled to act against the advice of the health professional, as long as it is not unreasonable for them to do so - the health professional's "consent" is not required.

Again, there is a danger is being misled by the Guide which states at one point: "To ensure that **decisions about access are made by appropriately qualified professionals**, the Act provides for access to be given by the health service body (...) after consultation with the appropriate health professional" (p7 - our emphasis). In relation to hospital records, the legal position is that it is the record holder who decides about access (after consultation) and not the "appropriate health professional".

Where access is allowed only to an "extract" of the health record, the Guide states that the extract "must be prepared by the health professional" (p21) - allowing the doctor in effect to decide what information should be passed on to the patient.

Obstacles to Gaining Access

To quote one CHC: "Whilst some control of access is necessary, the Act seems to have in-built obstacles, off-putting to other than the most persistent."

A Model Form for applicants is attached as Appendix 1 to the NHSME Guide although holders of health records are not required to use it. According to one CHC: "Application form for Access to Health Records presents a 'hurdle' for the less able applicant. It could be simplified". Another CHC reports that hospitals' application forms are "unclear and over complicated". Convoluted application forms could present particular problems for people whose first language is not English, whose sight is poor, who have learning difficulties or who are illiterate.

In some cases, there is a two-stage process as patients are required to write in before they can obtain the form to complete and return. One CHC reports: "One of the concerns we have is that a person has to write in with all the details regarding their records. A form is then sent to them. They then have to again put all the details on the form. This causes a considerable delay." Similarly, another CHC reports that patients requesting access to notes from one hospital suffer from its "peculiar system of having to write in for an application form (patients cannot just telephone). By the time the form arrives (assuming it does!), the 40 day limit may well be up".

However, another CHC reports that GPs in the area do not use application forms.

Obstruction and Ignorance

Patients may in practice find that the health professionals concerned do not appear to be acting in accordance with the Act. This may be genuinely due to ignorance of the Act's provisions on the professional's part - particularly in primary care. In some cases, however, the doctor or dentist may deliberately try to obstruct patient's efforts to exercise their legal rights. Problems experienced by CHCs include the following:

- Primary care practitioners "are frequently unaware of the patient's rights and their responsibilities. It is not unusual for practitioners to 'brush off' initial verbal access requests suggesting that access is not a patient's right or wanting to know why access is necessary...Dental X rays are usually provided under duress in their original form for the purpose of FHSA complaints. Dental X rays as listed in records are frequently 'lost'...I have had several cases whereby practitioners have totally ignored letters requesting access".

- "When access was requested to assist with a complaint about the GP, the record was 'lost'. When access requested for a GP complaint, patient was told she should do this via a solicitor. Non-compliance with request to see record by GP until CHC stepped in".

- "There have been occasions when I have had to remind providers of their obligations under the Act. One consultant from a children's hospital tried to refuse access unless the parents signed to say they would not take legal action".

- "Many record holders and administrators (especially those in primary health care - not least general practice) are not conversant with the provisions of the Act, nor often are they prepared to receive applications".

- Another CHC reports being told that the solicitor to a Trust "had informed staff that in his opinion people were using the Access to

Medical Records Act 'in the wrong way' as they were using the information to ascertain whether or not they should sue. Staff have, therefore, been advised to ask for the reason the records are needed".

- One cause of delay in the provision of records is the need, under the Act, to consider whether access would disclose "information relating to or provided by an individual, other than the patient, who could be identified from that information". This has been taken to mean that the record holder should seek permission to release records from everyone identifiable even including the health professionals involved in the case. However, the Act clearly states that this restriction on access "shall not apply...where that individual is a health professional who has been involved in the care of the patient" (Section 5(2)).

These incidents relate to cases in which CHCs have become involved and are likely to involve patients who are determined to discover and exercise their rights. Many other patients will have failed to obtain their records due to the ignorance or deliberate obstruction of their doctor or dentist. To rectify this will require a clear and user-friendly complaints system in relation to non-compliance with the Act and more publicity - not only in written English - to encourage patients to exercise their legal rights.

Delay

According to the Act, health records should be provided within 40 days of the date of application - or 21 days where the record has been added to in the previous 40 days. In practice, CHCs experience difficulties helping patients obtain health records even within these generous time limits.

- "Time limits (whether 21 or 40 days) to provide patients with access are sometimes woefully disregarded by some record holders and/or administrators".

- Another CHC reports that large providers seldom make records available "before the 'deadline' is up".

- "We often have to request the information two or even three times. If the request is in connection with the death of a loved one this delay causes frustration to the 'next of kin' and other members of the family who undoubtedly begin to wonder exactly why the delay is happening".

- "Our most recent example is of a client who was quoted 'up to six weeks' before the information would be available. This client's records had been updated within forty days of the request."

- "One of the biggest problems is keeping track of a patient's GP records, which are notorious for getting lost...Other delays in seeing the records occur if the patient is considering legal action. The records are shown to the service's solicitor before being shown to the patient."

- Similarly, in a letter to an applicant from a Trust's Medical Records Manager, the Manager states that before copies of the patient's record can be issued he needs to ask the applicant: "Is there likely to be any action against this Hospital or any of its employees? The reason for this question is that if there is any action contemplated then copies will have to be sent via the Regional Health Authority". The applicant's CHC took this up and the Trust Chief Executive replied: "You are quite right that there is no longer a need to check