

ASSOCIATION OF COMMUNITY HEALTH
COUNCILS FOR ENGLAND AND WALES



The Data Protection Act 1998

**Implications for Patients'
Rights
- A Briefing Paper**

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DATA PROTECTION ACT 1998

Implications for Patients' Rights - Briefing Paper

The Data Protection Act 1998 is not yet in force. The Government plan to implement it some time this year, although as yet, no date has been given. It will replace and expand on the provisions of the Data Protection Act 1984, repeal the Access to Personal Files Act 1987 and substantially repeal the Access to Health Records Act 1990. The amendments which result in the repeal of these two Acts were introduced on the Bill's passage through Parliament with no publicity or consultation. The lead Government Department is the Home Office.

The 1998 Data Protection Act is an attempt to implement the UK Government's duties as detailed in the European legislation on data protection – Directive 95/46 EC. The 1984 Act does not satisfy the requirements of this Directive and the Government decided to undertake a comprehensive review of all the UK data protection rules in the run up to passing the 1998 Act. A number of welcome new requirements are placed on the holders of records that contain information of a personal nature. The Data Protection Registrar will become the Data Protection Commissioner with wider powers to consider complaints by individuals who consider that their rights have been infringed and new powers to ensure compliance.

The Act will eventually apply to most records that contain identifiable personal data, whether they are to be stored in computerised form or manually. There are a number of clearly defined exceptions. However, those responsible for medical and social services records will have to comply with the Act's provisions, which include the right of the data subject to be informed that information is being held about them, the right to access their records and the right of confidentiality. The drafting of the Act is such as to cause concern about the way those rights will operate in practice.

Rights of Access to Information

Mentally Incapacitated Adults

Section 7(1) of the Act provides a right to access to the data subject to *'information constituting any personal data of which that individual is the data subject'* on written application and payment of a prescribed fee (likely to be set at a level of £10).

There is no express provision for applications for access to be made on behalf of others. The Home Office and Department of Health have stated that the rights of children, those without the mental capacity to make an application on their own behalf and those acting through agents will be protected through the application of the common law. While it is clear that the common law principle of agency will enable adults with capacity to authorise another person to make an application on their behalf, those without the mental capacity to make such request will not have the capacity to instruct another person to do so either.

Partly as a result of the inadequacies on the common law, the rights of access contained in the Access to Personal Files Act 1987 and associated Regulations and guidance and in the Access to Medical Records Act 1990 specifically provide that another person can make application for access so long as they are doing so in their capacity as the person appointed by a court to manage the affairs of the incapacitated person. This is not ideal, and has caused problems in many cases where the Court of Protection has not appointed a Receiver, or where the record holder has not recognised the legitimacy of the request made by carers and family members seeking to pursue the data subject's interests. However, even this limited right will no longer apply once the Act comes into force

ACHCEW has raised this issue with the Home Office, The Department of Health and with the Office of the Data Protection Registrar.

Disproportionate Effort

The statutory rights of access that are contained within the Act are subject to an exemption where the supply of the information would *'involve disproportionate effort'* – section 8(2)(a). What would amount to disproportionate effort is not detailed in the Act. Many NHS trusts, health authorities and GPs already complain that the supply of this information involves the use of scarce resources, which could be put to better use. ACHCEW has called for guidance outlining a clear duty on record holders to produce records.

Access to Original Records

A further concern arises from the wording of Section 7(1) of the Act in that it does not appear to give data subjects the right to access original records, but only *'information constituting any personal data'*. While this will usually not cause a problem, it may do where there are allegations that records have been tampered with or are inaccurate and where only access to the original record will be sufficient to resolve a question or dispute.

Accuracy

A related concern arises in relation to correction of records. Section 6 of the Access to Health Records Act 1990 gives the right to seek to have inaccuracies in records corrected. Inaccurate is defined as meaning incorrect, misleading or incomplete. Regulation 10 of the Access to Personal Files (Social Services) Regulations 1989 only requires the rectification of inaccurate information. Both require rectification by the record holder. The fourth data protection principle detailed in Schedule 1 of the Data Protection Act 1998 requires that information held shall be accurate. Section 14 of the Act provides that data subjects have the right to apply to the courts for an order that data be corrected, placing a greater burden on the data subject seeking correction.

The 1998 Act contains no requirement that omissions be remedied. ACHCEW has called for guidance to NHS record holders detailing the need to ensure that

records are not inaccurate through incompleteness. Likewise guidance should instruct record holders to ensure that records do not contain remarks that are irrelevant, discriminatory or obnoxious for some other reason.

Charges for Copies of Records

One of the main deterrents to patients wishing to access their own medical records are the charges which record holders in the NHS can make for access to and copies of these records. Presently NHS record holders are permitted to charge no more than £10 for access to records and no such charge may be made if the records have been added to in the previous 40 days. Charges allowed for copies are limited to the actual cost of making the copy.

At section 7(2) of the Data Protection Act 1998 provision is made for a fee to be charged for access to personal records. The Home Office has indicated that it is likely that regulations will set this fee at £10. The Act makes no mention of, or provision for, charges for the supply of copies of records. Section 3(4)(b) of the Access to Health Records Act 1990, currently provides for '*a fee not exceeding the cost of making the copy and (where applicable) the cost of posting...*' Although Department of Health Ministers have stated that patients should not lose rights or be disadvantaged under the new regime, officials at the Department of Health have indicated that they consider that the current system of charges for copies of health records disadvantages record holders. They would like to see guidance that permits higher charges. The Home Office supports this approach. The Office of the Data Protection Registrar would like copies to be made available within the £10 fee payable on access and have pointed out that the Directive requires Member States to guarantee the right to obtain information without excessive delay or *expense*.

ACHCEW has made representations to the effect that patients should not lose existing rights and that where possible these should be enhanced. A minimal fee or none at all, would ensure that data subjects have realistic rights and

reduce the administrative burden on record holders. We strongly object to any attempt to increase charges for the provision of copies.

Confidentiality

ACHCEW is concerned that under the provisions of the Data Protection Act 1998, some breaches of patient confidentiality will be permissible.

At present the right to confidentiality is not provided for in legislation and is governed by the common law (judge-made law). The common law governing confidentiality is convoluted and lacks clarity. In relation to medical records, the courts have relied heavily upon GMC guidance to doctors about their duty of confidentiality to their patients. This is currently under review and new guidance is likely to sanction disclosures that were previously frowned upon, such as disclosure to those carrying out financial audit of GPs. The Data Protection Act will impose a statutory duty of confidentiality on record holders based upon the common law. Schedule 1 of the Act details the data protection principles that will be generally applicable and legally binding on record holders. The first of these states

'Personal data shall be processed fairly and lawfully.'

The definition of processing includes disclosure of information.

While this is to be welcomed, ACHCEW considers that a chance to remedy the deficiencies and muddle that characterise the common law on confidentiality has been missed. The application of conditions before certain data can be disclosed is likely to cause even more confusion. The conditions provided in Schedules 2 and 3 give the impression that holders of records can dispense with the need for the consent of the data subject before disclosing personal identifiable information, so long as in the case of medical records, the disclosure is for *'medical purposes'*, which is defined to include research and management for healthcare purposes, if the record holder thinks disclosure is necessary *'for the exercise of functions of a minister of the*

Crown, or government department or ...any other functions of a public nature exercised in the public interest by any person.' or 'to protect the patient's vital interests' (which vital interests are not defined).

ACHCEW has called upon the Department of Health to issue clear guidance to the effect that medical record holders should obtain patient consent before making any disclosure beyond the team involved in that patient's diagnosis, treatment or care, except in those situations covered by statute (serious offences etc) and where the patient's consent is withheld unreasonably thus causing a serious block to clinical audit.

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