Current topic

Confidentiality and paediatric practice

A D M JACKSON

The 1984 Data Protection Act, which regulates the use of automatically processed personal information, has serious implications for medical practice. In response to the Act the Department of Health and Social Security (DHSS) set up an inter-professional working group to prepare a draft Code on the confidentiality of personal health information held in the National Health Service, which has been circulated for comment by the various health professions. The British Paediatric Association (BPA) opened its annual meeting in April 1985 with a discussion on the Act, the draft Code, and the whole subject of confidentiality as applied to paediatric practice.

Professor Forrester Cockburn, the convener of the Association's Standing Committee on Ethics, pointed out that as the Act did not specifically apply to health information the draft Code when fully discussed and approved would have to be incorporated as amendments to the Act. The Code, which deals with the disclosure of personal health information by health authority employees to third parties who are not so employed, would probably eventually apply to written as well as computerised records. The basic principle embodied in the Code is that, apart from certain exceptions, information may not, without the patient's consent, be disclosed to anyone for any purpose other than the health care of that patient.

It has been suggested that parents should have access to their children's records. Professor Cockburn believes that no problem would arise from parental access to factual records, apart from sensitive matters such as a positive test for syphilis in a member of the family. However, where the records include statements of opinion—for example, in cases of child abuse—and that opinion concerns the attitude or veracity of a parent, then it might not be in the child's interest to disclose them. If records are to be made freely available, therefore, it might become necessary for doctors to keep two case records, one for general information and one for medical use only.

Particular problems arise in relation to educational medicine. Paediatricians often participate in

discussions about children with teachers and educational psychologists, and the position regarding the sharing of information in the possession of the school health service will have to be clarified. The Code must be extended to include personnel who are at present designated as third parties to whom information may not be divulged.

In the field of research there should be a named person responsible for ensuring that personal health data are kept confidential within the research group, and all research projects should be subjected to the same ethical scrutiny as is research in general and hospital practice. This might raise problems for epidemiological research involving the collection of data from a number of different health authorities.

The draft Code does not include child abuse in the exceptions to the rules regarding disclosure of information, yet it is often essential in the interest of the child for information of a sensitive nature to be exchanged at child abuse case conferences in which lawyers and police officers may take part.

Registers of genetic disorders and handicap registers include information that refers to the families of patients and is capable of retrieval. This information is covered by the draft Code and may only be divulged if permission is granted or if one of the exceptions apply.

There are also special problems concerning the fetus, as information about the circumstances of fetal life relate to both mother and fetus. There might be occasions later in a child's life when he would seek information about events in his mother's pregnancy, and Professor Cockburn suggested that in such cases disclosure of the mother's clinical records could be reasonable and should be made an exception within the Code.

The minimum age at which a child can legally give consent to medical treatment independently of a parent is 16 years in England and Wales. Scottish law, however, recognises that at puberty (defined as 12 years for a girl and 14 years for a boy) a child may enter into some contracts on his or her own behalf, so that a girl under the age of 16 who is capable of rational judgment may give independent consent to medical treatment and the provision of contracep-

tion. Professor Cockburn concluded by stressing the importance of ensuring that the DHSS Code will be made relevant to these special problems in paediatric practice.

Mrs Diana Brahams, who is a barrister and legal correspondent of the *Lancet*, discussed the Gillick case. Dr John Dawson, an under secretary of the British Medical Association, discussed the draft Code. Information about a patient held by a health authority must not be disclosed, without the patient's consent, to third parties, that is to say anyone who is not an employee or member of the health authority concerned. In practice this will apply mainly to hospital records.

The other principles embodied in the draft Code are:

- (1) Professional employees of a health authority have an obligation to ensure that personal health data are disclosed only to those who need them for health care of the patient.
- (2) Health professionals entrust personal health data to health authorities only on the understanding that the patient's confidences and the professional's corresponding obligations will be respected.
- (3) Personal health data relating to a person other than the patient and held in the patient's health records must not be disclosed, even with the patient's consent, to anyone for any purpose other than the health care of that patient.

There are a number of exceptions to the application of these principles:

- (a) Disclosure required by statute.
- (b) Disclosure ordered by a court of law.
- (c) Disclosure that is necessary for the investigation of a complaint or other essential management function.
- (d) Disclosure authorised by an ethical committee for research purposes provided there is anonymity for the subject and no damage or distress will be caused to him.

- (e) Disclosure for the prevention or detection of a serious crime.
- (f) Disclosure to safeguard national security.
- (g) Disclosure to prevent serious risk to public health.

In Dr Dawson's view health professionals should follow certain simple rules. They should tell the truth, accept responsibility for their acts, respect the autonomy of the patient, and not exploit the power of professional status. He considers that health records are held in trust for the patient; they are not the property of the doctor, and it is reasonable that the subject should have right of access to them.

Laws are not immutable and must change as society changes. While they are a blunt instrument for solving individual dilemmas they can be created and modified to provide a framework for professional action. In conclusion Dr Dawson pleaded for a national ethical committee that could propose changes in the law, give approval for research projects, and draw up guidelines for practice.

In the discussion that followed it was stressed that no reference was made in the draft Code to the embryo, the fetus, or the child. The confidentiality of health data on patients under the age of 16 needed to be clarified. There was strong support for extending the Code to cover the disclosure of information by health professionals to third parties in case conferences or in multidisciplinary assessment teams for handicapped children. There were particular problems of confidentiality in respect of children who were in care or were being considered for adoption or fostering. Some members of the audience considered that health information should only be disclosed to social workers if confidentiality could be guaranteed or if the recipient were known and trusted by the informant.

The right of parents to have access to the health records of their children raised problems for a number of paediatricians. They agreed with Professor Cockburn that such records included opinion, deduction, and surmise as well as facts and it would not necessarily be in the child's best interest for the parent to see all of these.