

Who owns the patient's record?

FROM time to time the College is invited to give an opinion about some ethical aspect of health or medical care. When opinions in society are sharply divided, for example about whether or not experiments on the fetus are to be permitted, it is manifestly impossible for the College to take a view: its membership is as likely as society to exhibit a range of deeply held and conflicting convictions.

Even on questions which might be held to unite the medical profession, for example whether or not the government should spend a larger proportion of the budget on medical care, it would be unwise to assume that the College could speak for its membership with real confidence. In attempting to answer ethical questions, each individual may express values and beliefs with the conviction of self-evident truths or divine revelation. When the College is asked to give an opinion on such issues, it is usually wiser to attempt an analysis of the questions and a discussion of the values, than simply to count votes.

Recently the College was asked to give support to the Access to Personal Files Bill, which was to be debated later this year in the House of Commons. I was invited to produce a memorandum on the subject for the General Purposes Committee of Council, and subsequently to publish a version of this in the *Journal*. The intention is to invite the comments of College members. These should now be directed to the Honorary Secretary of Council.

The Data Protection Act gives a person the right to see personal data about him/herself which has been recorded in a form which can be processed by equipment operating automatically: that is to say data held on computers. In its response to the Department of Health and Social Security discussion document on this Act, the College supported the right of access of clients and patients to all information held about them, but believed that this access should be modified. Data generated by professionals about the physical or mental health of the patient might be withheld by the physician in charge of the case, when in his/her view the release of these data would: (1) cause distress or harm to the patient, either physical or mental; (2) seriously prejudice the continuation of a meaningful doctor-patient relationship.

The College accepted that any code of practice governing computer-held data would in the future apply also to so-called manual systems. It is this extension to manual systems which now requires examination.

Those who argue for open access appear to do so on the following grounds. First, individuals have a right to know what is said about them in personal terms, about their state of health and about their prognosis. These data are not the private property of health care professionals, institutions or organizations, but are in effect the property of the subject.

Secondly, if open access to information is withheld, the patient is deprived of important data, without which it might be impossible to make informed choices. To withhold such open access is to deprive the patient of the level of autonomy which a modern citizen expects in our society.

Thirdly, the accuracy of the information in the medical record could be improved by sharing that information with the patient. Inaccurate or misleading information may be accidentally recorded by doctors and nurses, and open access will permit the patient to question and correct this information. The quality

of the record and its effectiveness in health care will therefore be enhanced.

Finally, the absence of open access makes it possible for health care professionals to record data which are defamatory to the character of the subject. These can prejudice the attitudes of other health care workers, and are potentially harmful. Open access, presumably because of the threat of embarrassment and litigation, would make the recording of such defamatory statements unlikely.

While these arguments have considerable power, so do the arguments against open access. First, it is argued that laymen may be unable to cope with the data recorded. The reasons may be technical — professional language can be obscure or worse still misleading; intellectual — the subject may not be able to understand the meaning of what is recorded, even when non-technical language is employed; or emotional — the data recorded may be disturbing or even frightening.

Secondly, recorded data in medical records are not simply facts. Professionals are often required to record opinions and best guesses which may be interpreted by the patients as carrying the weight of established facts. Yet to omit them from the open-access record would render these records less useful as tools for diagnosis and management.

Thirdly, the patients' medical record often contains information derived from a third party, or information which concerns a third party. For example the doctor may record that the patient's wife has reported that her husband has been drinking excessively. Or she may suggest to the doctor that her husband's alcoholism is related to her own health, behaviour or feelings. Both sorts of communication may be privileged. If the medical record is seen as the property of the patient, whose property are these data which concern third parties? If the patient has open access to them not only is there a risk of harm to the patient (who may accept the risk) but there is a risk of harm to the others whose confidentiality may thus be breached.

Fourthly, sound clinical problem solving (particularly in general practice) demands that the doctor tolerate uncertainty and take small but acceptable risks. If the doctor records the uncertainty he tolerates, he may create harmful anxiety in the patient or he may court litigation. If he practices defensively, he may harm the patient by excessive investigation and treatment.

Finally, those who claim that the patient owns his own record are not on absolutely sure ground. A medical record is not a simple transcription of the patient's story. In order to create a medical record this story must be transformed, ordered and interpreted by the doctor and other health care workers. The patient may be thought to have the right of access to personal information about himself. But the record also contains personal information about the doctor — his thought processes, values and judgements. Just as the patient has the right not to disclose part of his story, so the doctor may have the right not to disclose part of his interpretation.

The arguments for and against open access are made with the best interests of the patient in mind. But who is to determine these best interests and how influential should be the voice of the professionals (doctors, nurses and social workers) in determining social policy? There are arguments which suggest that open access to the medical record can improve the quality of care, and arguments which suggest that open access may compromise the quality of care. The law may decide between these arguments, but it is unlikely to resolve the dilemmas.

There is a footnote which has important practical consequences for general practice. It is one thing to legislate for open access to information which is held on computers. It is quite another to open to patient access records created in the past by health care professionals, when there was no such expectation. These past records will almost certainly contain data which would have been excluded had the health care professionals concerned expected open access.

If manual records are to be open in the future, general practitioners might be obliged, prior to that legislation, to reform all their past records, summarizing the data which are relevant, editing data which might be prejudicial and defamatory, and

ensuring that relevant data are recorded in clear and unambiguous language.

Although some valuable insights and information would be removed from such reformed records, they would nonetheless constitute a significant improvement on the vast majority of contemporary records. Perhaps we should earnestly hope that society will force this change on the profession. We should of course need to remind government of the considerable resource implications. Resource allocation is most often discussed in economic terms. It is of course an ethical issue.

MARSHALL MARINKER
Director, The MSD Foundation

Community children's homes

THE report of the Social Services Inspectorate of the Department of Health and Social Security on their inspection of community homes has been produced with commendable speed. During the last quarter of 1984 the inspectorate visited 149 community homes in 29 local authorities — 13% of all local authority community homes. The thoroughness of the inspection is equalled by the frankness of the report, which time and again surprises the reader by its sympathetic handling of this most difficult area of care. It deals with what is good and what is bad in these homes, and includes a detailed section on the provision of health care in which there is implied criticism of the general practitioners who provide medical services to these homes.

The inspection took place at a time of change — all the local authorities involved were reformulating their child care policies or had recently done so. Most were moving towards reducing the amount of residential provision in their areas and also trying to reduce the length of stay of the children in their homes.

A further factor was the change which had taken place in the populations of the homes in recent years. At the time of the survey 80% of the children were aged 13 years or over. The traditional image of a 'children's' home must now be altered to take account of the now predominantly teenage population.

The inspectorate also found that the care staff were faced with a change in their traditional role. The substitute parenting role of previous years needed to be developed to prepare them for dealing with the older children, many of whom had experienced a succession of broken relationships, both before and after coming into care. There were many examples of disruptive and delinquent behaviour, of depression and self-abuse, of drug, solvent and alcohol misuse, school refusal and promiscuity. The staffing of the homes had also changed; 98% of staff were now non-resident, two-thirds were aged under 40 years and the ratio of men to women was 1:2. On the whole the inspectorate reported that staff were under-qualified and staffing cover was barely adequate in most homes.

Unfortunately, the inspectors found that the majority of premises visited were in poor shape, many were cramped and some over-crowded with a poor general standard of furnishing. Despite this the life-style in most homes was in keeping with the age group of the residents; regimes were child centered and control was maintained on the basis of good personal relationships.

The arrangements for health care in the homes were looked at carefully by a senior medical officer and nursing officer, and they have made many recommendations. It would seem that all children had easy access to a general practitioner, but in a few homes the local general practitioners only signed the children

on as temporary residents, a situation which was felt to be unsatisfactory.

Some local authorities appointed general practitioners as visiting medical officers. The inspectors were worried about the role of these general practitioners, who in most cases provided the usual general practice services and routine medical examinations. They were critical of the fact that visiting medical officers often made no attempt to collate medical records, examine vision or hearing or investigate the immunization status of the children. They propose that local policies should incorporate the idea of a coordinator for each home, who would obtain the past medical history, maintain a brief record while the child was in the home and make sure that there were no gaps in the health record so that no child would reach the age of 16 years without a full assessment having been made. The coordinator would be appointed either from the social services department or from the health service but would be non-medical.

The report also recommends that discussion should take place between the district health authority and the social services department on the form and content of psychiatric and psychological support needed. A suggested solution would be to appoint a psychiatric adviser to the local authority and to develop closer contacts with the local child guidance clinics. Clear links would also be established with the health education officer of the district health authority for advice, support, information and in-service training in health matters, particularly with regard to drugs, solvent and alcohol misuse and smoking.

Arrangements would also be made for staff to receive advice and help in dealing with the development of sexuality and with information and support on specific subjects, such as contraception, pregnancy and sexually transmitted diseases.

General practitioner services would be required to treat illness and arrange referral to specialist advice but the role of the visiting medical officer was regarded as out-dated. Child development needs would be met by the combined efforts of the local authority and district health authority staff.

This is an excellent report giving a penetrating insight into the workings of local authority community homes and their clients. This report is to be sent to all local authority and district health authority general managers and the recommendations, if implemented, will improve the quality of care being given in children's homes. General practitioners involved in this work would do well to take careful note of the health care recommendations as they would appear to be critical of the present medical care being offered.

MARTIN E. BARKER
General Practitioner, Stamford, Lincolnshire