

remove jewellery of possible religious importance from children and from patients too ill to object. The new campaign should help to educate and persuade Asian women to attend early for antenatal care; unless they do so early detection of obstetric abnormalities and screening for congenital malformations, genetically determined disorders, and chromosomal abnormalities is not possible. The Birmingham work has shown the need for further investigation into the cause of stillbirths in Indian women.²

It is not only the communities from the Indian sub-continent who need help, however: isolated Chinese families in small towns may have great difficulty in making effective use of the medical and social services. The Vietnamese are still trying to create their own communities and to repair the damage caused by the disastrous policy of dispersal which the government adopted for the "Boat People."⁶

Our medical and nursing schools still give little formal instruction in the religious beliefs and cultural patterns and in the medical and emotional problems of our Asian and other ethnic minorities. The conference at the Royal College of Obstetricians and Gynaecologists in 1981 on "Obstetric Problems of the Asian Communities in Britain,"⁷ and the conference on "Diseases in Ethnic Minorities" in May of this year at the Royal College of Physicians in London indicate an awakening of interest. Even so, this important subject still does not receive the attention which our patients deserve.

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- 1 Social Services Committee. *Perinatal and neonatal mortality. Second report from the Social Services Committee, 1979-80*. London: HMSO, 1980:107. (Short report.)
- 2 Terry PB, Condie RG, Sattatree RS. Analysis of ethnic differences in perinatal statistics. *Br Med J* 1980;281:1307-9.
- 3 Terry PB, Condie RG, Mathew PM, Bissenden JG. Ethnic differences in the distribution of congenital malformations. *Postgrad Med J* 1983;59:657-8.
- 4 Watson E. Health of infants and use of health services by mothers of different ethnic groups in east London. *Community Med* 1984;6:127-35.
- 5 Winkler F, Yung J. Advising Asian mothers. *Health and Social Services Journal* 1981;91:1244-5.
- 6 Owen L. Boat family sails into British storm. *Observer* 1984 June 24:3 (cols 7-8).
- 7 McFadyen IR, MacVicar J. *Obstetric problems of the Asian community in Britain*. London: Royal College of Obstetricians and Gynaecologists, 1982.

Confidentiality of personal health information

The Data Protection Act of 1984 (which regulated the use of automatically processed personal information) was seen to be inadequate for the problem of medical information. Hence an inter-professional working group was set up under the chairmanship of Sir Douglas Black to draft appropriate amendments.

A draft code has now been circulated for comment by the medical, dental, and nursing professions and by health service administrators. Health authorities have been asked to consider whether the code should apply only to automatically processed data or to manual records as well. The Department of Health and Social Security also wants to know whether the inclusion of manual records under the code would add unacceptably to the cost of implementation. Last month the Steering Group on Health Services Information (p 1559) published a further report, *The Protection and Maintenance of Confidentiality of Patient and Employee Data*, which sets out the practical implications of the draft code.¹

The code opens with five pages of principles densely worded in legal phraseology. These are followed by a set of

supplementary notes designed to amplify the principles. These are based on two fundamental concepts: the need to know and the patient's right to confidentiality.

The basic principle is that a health authority holds information about a patient only for the purpose of health care; the patient has a right to have that information kept confidential and not disclosed to third parties without his consent. The health authorities have a duty to respect that right. Professionally qualified staff employed by the health authority have obligations to keep personal health data confidential and to ensure that these are disclosed only to those who need them for the health care of the patient. Health professionals entrust personal data to health authorities only on the understanding that those authorities will respect the patient's confidentiality and recognise the obligation that professional staff owe to their patients.

The patient has a right to expect that personal data entrusted to health authorities will not be disclosed to members and employees of the authority for reasons other than his health care. He also has the right that any information concerning another person connected with him—for example, a sick wife—should be protected by the same confidentiality as his own personal information.

These principles should give extensive protection of the patient's personal data, but the draft code recognises exceptional circumstances in which information might reasonably be disclosed to third parties. Disclosure may be required (not merely permitted) under statute—for example, in the notification of infectious diseases under the Public Health Acts. Agencies such as the Health Service Commissioner can require the provision of personal health data. In these circumstances health authorities are not required to obtain consent—but they would normally notify the patient and the health care professional when practicable.

Disclosure may also be ordered by a court of law or by a person empowered by statute to require its disclosure—for example, the coroner's court. Here again the patient's consent is not required, but he should be informed so that should the information not be required it can be set aside by the court. Disclosure may also be necessary for investigation of complaints and for essential management functions—for example, maintaining the local authority register of disabled persons. Here again the patient's consent is not essential.

Disclosure may be authorised by the appropriate ethical committee (which must include lay members) for health research. The provisos are that no damage or distress will be caused to the patient and that the patient's anonymity is preserved in published work. Furthermore, the ethical committee must ensure that consent is obtained from the professionally qualified person who collected the health data in the first place. No approach should be made to the patient without the consent of the professionally qualified person responsible for that aspect of his health care (or perhaps his general practitioner). If personal health data are disclosed to a research team then these must not be disclosed to anybody outside the research team and must be adequately secured against unauthorised access. They must also be destroyed when no longer needed.

Exceptionally, the disclosure of personal health data may be justified if it can help prevent or detect serious crime or bring the perpetrator to justice. For this to be appropriate the crime must be sufficiently serious and it must be established that without the personal health data the task of preventing or detecting the crime would be prejudiced, delayed, or impossible. Again, such disclosure requires the consent of the health care professional responsible for that aspect of the

patient's health. In the rare event that personal health data have a bearing on national security the health care professional must disclose the relevant data when given convincing evidence of the importance of such a disclosure in the shape of a certificate signed personally by a cabinet minister, the Attorney General, or the Lord Advocate.

Personal health data may need to be disclosed to prevent serious risk to public health—for example, in the prevention or control of communicable diseases. Again disclosure is allowed only with the agreement of the professionally qualified person concerned.

Having defined broad principles and a restricted number of exceptions, the code suggests that suitable management arrangements must be established to ensure that all disclosures of personal health data are made strictly according to the code. Health authorities will need to establish precisely who will receive requests for disclosure of personal health data and who (not necessarily the same person) will define whether such a disclosure should actually be made. Furthermore, contingency arrangements for delegation must be made if these persons are not available.

Records must be kept of all disclosures so that not only can the code be kept but it can be seen to be kept. Health authorities will have a duty to publish details of disclosures at yearly intervals. Health authorities must also ensure that their employees are aware of the code and that disciplinary action may be taken if it is broken.

My first impression is that this document probably means far more to the lawyer than it does to the layman. How many people will understand its provisions without recourse to legal opinion?

One of the useful functions of such a document, however, is to remind each of us of the extent to which our own personal health data may already be flowing into unexpected places. After all, the code is intended to regularise existing practices and presumably control them. Am I unconsciously a statistic in somebody's research project?

The detection, prevention, and prosecution of "serious crime" are exceptional circumstances in which the code allows personal health data to be disclosed without the patient's knowledge. The professionally qualified person has to be convinced of the seriousness of the crime before disclosure is made, albeit with the code's guidance "... for the public interest to prevail." In the haste to help detect crime might a doctor be got from his bed by the police and asked to decide speedily on the reasonableness of disclosure? Furthermore, when the annual statistics on disclosure are published, will that doctor's name be mentioned? Might such a disclosure lead to the prosecution of a patient—his own personal data acting against him, for example, in a case of drug trafficking?

The code consistently uses the term "professionally qualified" in the preamble and defines this as meaning a doctor, nurse, midwife, or a dentist but also a clinical psychologist or a social worker. According to the code each of these (and presumably more categories, because the code comments that the list is incomplete) is capable of deciding whether information should be disclosed. Will a nurse or a clinical psychologist feel competent to judge the importance or even the accuracy of specifically medical information, and vice versa? Perhaps subsequent versions of this code will state that the professionally qualified health care person will only release information in his or her own special discipline.

Many patients might be surprised that control of the disclosure of information is not entirely vested in the hands of the medical profession. Some patients may not recognise the

extent to which their personal data are already preserved by all members of the health care team.

Perhaps the most pressing question, however, is whether the code should apply only to automatically processed data or whether it should cover manual records as well. I am surprised that anyone should ask whether manual records should be included within the umbrella of confidentiality along with records on automated media. Surely one either protects the patient's personal data or one does not. Whether the record is on paper or on computer makes little difference. The difference is one of accessibility, manual data being easier to get at. Computer data provide access to many records quickly. The overriding principle, however, is still that doctors and other health professionals must protect the confidentiality of their patients.

The cost of confidentiality and its maintenance with manual records should be virtually nothing; information on patients is already regularly handled in administrative and medical departments and the staff who are handling it should already be conscious of the need for confidentiality. Hence the main new cost should be that of reminding the staff of the need for confidentiality according to the code. Another cost will be for training programmes, if only to explain the legal language in the code, and a third cost will be for publishing the disclosures.

In general, this draft document should be welcomed as a sensible start along the road of protecting the patient's confidentiality. When the amended code becomes available doctors will have to be aware of its guidelines, and a simpler document will be needed and should be distributed, say, to all newly qualified doctors.

A JOHN ASBURY

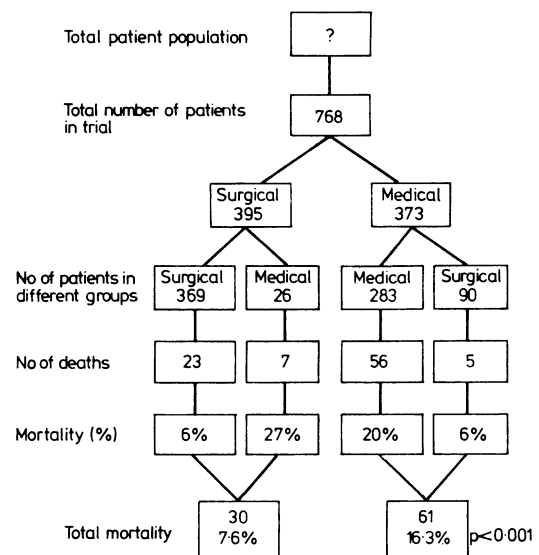
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1 Steering Group on Health Services Information. *The protection and maintenance of confidentiality of patient and employee data*. London: HMSO, 1984.

Correction

Coronary artery bypass grafting for the reduction of mortality: an analysis of the trials

We regret that an error occurred in this Regular Review by Professor J R Hampton (3 November, p 1166). In the diagram showing the results of the European Coronary Surgery Study (five year follow up) the outcomes for patients in the medical group were accidentally transposed. They should have appeared as in the accompanying figure.



European Coronary Surgery Study.