Letter from Westminster

Protecting personal data

WILLIAM RUSSELL

The doubts that the medical profession has about the Data Protection Bill, which started its parliamentary passage in the House of Lords this week, have been widely aired. The Bill, which enables the United Kingdom to ratify the European convention for the protection of individuals with regard to automatic processing of personal data, establishes a data protection registrar. His job will be to set up a register of personal data users and computer bureaux, and he will have powers to ensure that such information is not abused. A data user who registers will also have to register the bodies to whom the information he holds is made available.

The Bill, of course, covers far more than medical or other data stored in computers, but it does not deal with information of any kind held manually. This is seen by some doctors as a flaw. At present, perhaps only 5% of all NHS records are stored in computers and for general practitioners the same is probably also the case. The use of computers, however, is advancing apace, and so far as the government is concerned the task of devising a system to cover manual records is one of mind boggling complexity. It thinks that the need to protect computerised data is urgent, and that it would have been quite impossible to deal with manual and computer held records in the same piece of legislation.

The Bill is frankly rather vague on medical records. The relevant clause, number 29, leaves it to the Secretary of State to decide by order what will actually happen. This will define what access the individual may have and how he may have it.

The White Paper on data protection was published last April. The Bill was published just before the House rose for the Christmas recess, and the intervening months were spent in consultation with interested bodies about the form it should take. The medical profession, it is alleged, was not one of the speediest in coming forward with its views on how things should be done during this time, hence the vagueness on the handling of medical records. Discussions are still going on, but by the time the government is ready to lay the orders they will have been completed. The Bill is expected to become law by the summer, but a registrar will then have to be appointed and he will have to establish his office.

One suggestion being looked at is that an order could lay down the method by which information is provided in sensitive cases. It is possible that a patient seeking access would have to do so through a doctor of his choice, who would then relay it to him. This would avoid somebody being told something that could affect his condition from a computer printout. The Secretary of State will also by order be able to exempt certain kinds of medical record from being available, if that is thought desirable. The orders will be subject to what is called the affirmative procedure, which means that they will have to be debated. This usually happens late at night, but it is some safeguard against dictatorial executive action.

There was a passage in the White Paper that was interpreted as meaning that doctors could be compelled to disclose medical

records to the police, a belief that clause 28 of the Bill has not helped to dispel. The government claims that those who think this have misread the White Paper and the Bill, and all that clause 28 provides is that where data essential to the solution of a criminal offence are required by the police a doctor who holds them may pass the information on without incurring the penalties for giving it to a non-registered recipient.

The government claims that it is neither practicable nor desirable to decree that everyone who registers must include the police among those who receive information. The Bill contains a safeguard for the individual, again to be brought into being by order, if experience proves it is required. This lists certain kinds of information that may not be released without the consent of the person concerned and would relate to data on his physical or mental health or sexual life.

Social Democrats and health

The Social Democrats are to hold their policy making council next weekend (29 and 30 January) in Newcastle upon Tyne, when the health policy statement that they issued last autumn comes up for ratification. There have been several changes since it appeared, including a whole new section on primary and community care. This proposes the establishment of complete teams of professionals—general practitioners, nurses, midwives, health visitors, and social workers helped by pharmacists—who would work with voluntary organisations and local individual volunteers. The aim would be to pick up problems as early as possible, to prevent as many as possible from arising, and to treat as many patients as possible in their own homes or in the practice rather than refer them to hospitals.

The document identifies the fiercely defended independent status of general practitioners as one of the obstacles in the way of getting the medical profession's cooperation.

"One consequence of this has been the lack of information about general practice," the document says. "Very little is known about the impact of investing in primary care. A symbol of general practitioners' independence is the separation of family practitioner committees from the main structure of the NHS, which we believe will be made more seriously divisive by the Conservatives' current legislative proposals. Yet general practitioners themselves face increasing problems. They are suffering from isolation from the mainstream of the Health Service."

The document emphasises that the Social Democrats are not looking for battles about the family practitioner committees and do not have any desire to be dogmatic. They seek a willingness to experiment and test out new ideas on the part of general practitioners. These would include the use of salaried general practitioners in the inner cities, more item of service payments to encourage them to look after the chronically ill in the community or to carry out tests and minor procedures that would otherwise have to be done in hospitals, and joining in experiments to monitor just what it is a general practitioner does. "There is great scope for enthusiasm and imagination and we will give bold, new approaches room to grow," the SDP promises.