ETHICAL IMPLICATIONS OF RESEARCH IN PSYCHIATRIC EPIDEMIOLOGY

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BASIC PRINCIPLES

The ethical issues in psychiatric epidemiology are the same as those arising from the more general use of medical information for research - informed consent and confidentiality. In 1972, the MRC of the UK set out their views on these matters in a paper that has been widely influential (1973). They have recently been reviewing this paper but have not found it necessary to make substantial changes. During the intervening ten years no breach of medical confidence or instance of harm or distress to patients has been reported to the Council's Standing Committee.

Nevertheless, there has continued to be considerable public concern about a possible misuse of medical information by people or authorities who do not have patients' interests at heart. The ease with which identifiable records can be held on computers has amplified the problem particularly when the computer files are under government control.

Helmchen and Oerlinghausen (1975) have pointed out that it is a doctor's duty to be well-informed. This, too, is an ethical obligation. Part of the knowledge on which good clinical practice is based can only be obtained by pooling the experience of many doctors and by conducting epidemiological studies and health services research. In order to undertake good research, it is often necessary to link records made at different times by different people about one individual patient and it is not always practicable to obtain informed consent for each specific act of transfer of information. The facts made available by patient to doctor during the course of a clinical consultation sometimes
cannot and ethically should not be used only within the context of that personal relationship.

The concept of extended confidence is essential to a discussion of privacy. Behind clinical medical practice there stands an implied band of trust between the public and the medical profession, as well as the individual's confidence in his or her own doctor. It is assumed that the actions of the responsible doctor are intended to be beneficial and that no harm will result from them. These actions include the passing of confidential data to other people who, in turn, will act responsibly since they would not otherwise be given the information.

This trust is stronger in some countries than in others. Every nation gets the government and the medical profession that it deserves. I can speak from personal experience only about the United Kingdom, where the principle of extended confidence is accepted, although with much caution and an insistence on safeguards. In order to ensure that no harm can come to patients it is necessary to adhere strictly to a code of practice (Baldwin, Leff and Wing, 1976).

Misuse could occur at three main levels, each of which needs consideration.

CLINICAL SETTINGS

Probably the highest risks in individual cases arise from lapses of security in hospitals, clinics or medical practitioners' offices, where medical records may be left carelessly around for unauthorized persons to read, or in lax standards of security being applied to medical information transferred to non-medical professionals. However, the possibility of deliberate burglary should be considered. All hospitals and practitioners should carry out a review of their security precautions in order to be sure that these risks are reduced to a minimum. It should be standard practice that medical records should be kept under secure conditions at all times when they are not actually being used by an authorized person.

A small-scale survey of patients or of medical records is equally vulnerable to careless lapses and the same security precautions should be taken as for larger scale information systems.

INFORMATION SYSTEMS UNDER MEDICAL CONTROL

Whenever a more formal information system is set up, which requires the collection of identifiable data and especially if