The Use of Human Subjects

The conflict between the individual’s right of privacy and the requirements of research involving human subjects was the theme of an address* at the recent AAAS meeting by Oscar M. Ruebhausen, a member of the New York Bar who has devoted special attention to the relations between science and law. He advised scientists to get busy and establish standards to govern the use of human subjects, and promised that if their standards are adequate they “will rank high in relevance for a court of law.” But he also warned that if they “are not thought to measure up to the values of the community . . . it is probable that the judges will, themselves, seek to devise the necessary standards to give effect to the community’s values.”

A range of rights must be considered. The individual’s right to control the use of his own property and to preserve his own physical integrity have long been recognized. More recently, the courts have been coming to recognize a right of privacy of personality. There is also a range of research activities—in medicine, biology, psychology, sociology, and perhaps also anthropology—that may be thought to invade privacy unless there be proper consent, for the right of privacy is really the right of an individual to decide how he will share his privacy or what intrusions or exposures he will permit.

The several disciplines differ somewhat in their research requirements, but it would be dangerous for them to work alone in establishing standards. The reason is partly that no firm boundary separates man’s biological and psychological natures and partly that standards adopted by one discipline are likely to be applied by the law to other disciplines.

Medicine has accumulated much wisdom in the use of private and confidential data concerning patients. If scientists are to develop satisfactory standards, they will take account of medical experience. If scientists fail to develop satisfactory standards, the judges will probably take too much account of it. If the judges find the scientists’ standards unsatisfactory, they are likely to turn to medicine for their model, and that model is incomplete.

A recent study† of the attitudes of physicians toward their patients confirms the fact that the physician considers his overriding responsibility to be the individual patients with whom he is working at the time. This is exactly what we wish of physicians. But when we are concerned with public health or the advancement of knowledge we want to be assured that experimental methods and controls are adequate.

The relation of doctor to patient need not be challenged by biomedical or behavioral research, but the distinction between this relationship and the relationship of researcher to subject must not be confused. It will be difficult to maintain this distinction clearly, to satisfy research needs, and to assure society that the rights of privacy are fully protected. But if by default, because the job is difficult, the judges are left to decide matters on the basis of their traditions and the experience of medical practice, progress in science and its applications to human welfare will be retarded.—DAEL WOLFE

† Amasa B. Ford et al., The Doctor’s Perspective (Case Western Reserve University Press, Cleveland, Ohio, 1967).