Guidelines on health databases must consider developing countries

Developing countries must be given special consideration when drawing up guidelines on centralized health databases, warned delegates of the World Health Organization and the World Medical Association at a joint seminar on the ethical implications and optimal design of centralized health databases. The seminar was held in May at the headquarters of WHO, in Geneva.

"WHO has a special responsibility for developing countries, where regulatory frameworks and technical expertise may be scarce, and the level of public awareness, education, and sophistication may be low," explained Dr Daniel Wikler, senior ethicist at WHO. "Developing countries must receive particular attention because current initiatives in wealthy countries might serve as precedents for similar undertakings in developing countries. The interests of developing countries need special attention also because firms and agencies now gaining experience in developed countries may turn to populations in poorer countries in the course of research initiatives".

Representatives from both organizations debated whether producing international ethical guidelines on the use of health databases would be a valuable next step in protecting the public and allowing scientific research to continue. Health databases have been an indispensable resource for researchers over many years, but recent progress in genetics has sparked public fears that the information on these databases could be abused.

Only last year, the government of Iceland awarded a private company, deCODE genetics, an exclusive licence to establish a database of genetic and genealogical data for the whole population. Because of its unique history — mostly of isolation — Iceland is of particular interest to researchers. The ethics of awarding the licence to a private company have been questioned, however.

"Centralized health databases can make a tremendous contribution to the improvement of health through a better scientific understanding of the causes of disease and illness," said Dr Anders Milton, chairman of the World Medical Association. "But the public's right to privacy and consent are essential to the trust and integrity of the patient/physician relationship. Guidelines must address the issues of informed consent, privacy, confidentiality, individual access, and accountability on the part of the owner of the database".

A working group from the World Medical Association will present draft guidelines to the World Medical Association's annual general meeting at Edinburgh in October 2000. ■

Kamran Abbasi, *Bulletin*