Foreword

The Responsibilities of Epidemiologists

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Biomedical research activities are guided by internationally recognized principles of human ethics, as embodied in the Declaration of Helsinki, and in the proposed International Guidelines for Biomedical Research Involving Human Subjects, prepared by CIOMS in 1982. Existing codes of ethics have hitherto tended to focus mainly on the rights and interests of individuals. In the same way that levels of ethical responsibility have been proposed for physicians, four levels of responsibility and liability may be considered for those epidemiologists—in the wider sense of the term—who undertake epidemiological research or apply the results of this research in the community.

First, as *technical experts*, those who practice epidemiology must provide information, as factual and as accurate as possible, to policy-makers and planners, to program managers and to the public. And consideration must be given as to how their liability for studies can be properly assured.

Secondly, as *citizens* in their country or community, they have a responsibility to work for the good of those they serve, and must therefore respect the values of their community and their country.

Thirdly, as *actors in the implementation* of health and socioeconomic programs, they have to help in interpreting health policy and in making difficult choices, balancing the rights and interests of individuals with those of society; they also have to make data available for coordination, monitoring and evaluation of programs.

Finally, like all human beings, they have a role to play as *morally accountable* persons. They must remain faithful to humanitarian principles and values, pertinent, not only to themselves, but to the persons and communities involved in their work, and indeed to all mankind. This includes maintaining professional confidentiality.

If these four levels of responsibility are kept firmly in mind, I think we shall be basically on the right track. The challenge, then, will be to develop approaches to epidemiological research and application of its outcome which respect the following three elements of ethics:

(i) *respect of persons*, such as the right of individuals and groups to be informed and to have a say in their involvement, with particular safeguards for persons with impaired autonomy;

(ii) *beneficence*, that is to say, the requirement that benefits outweigh cost or harm; this can be considered the equivalent or counterpart to the Hippocratic principle of "do no harm";

(iii) *justice*, that is to say, the obligation to protect the weak and to ensure *equity* in rights and benefits, both for groups and for individuals.

The purpose of this symposium is to extend the consideration of ethical principles and procedures to the undertaking and application of epidemiological studies in communities and populations. This extension does not change the basic principles of ethics and human rights; it adds larger dimensions, such as the rights of populations in regard to health, and the integrity of individuals and communities, including freedom to decide. In the exercise of these rights, there is a close interaction between the rights of the group and the rights of individuals.

Many ethical issues, as regards both the individual and the community, are clearly emerging from current health problems, including the AIDS pandemic. Issues of screening, testing, participation in clinical trials and confidentiality all raise questions as to how to apply basic ethical principles in the context of AIDS. These questions are a matter of concern to increasing numbers of patients, practitioners, researchers and policy-makers.

Particularly in epidemiology, it must be increasingly and explicitly recognized that problems of ethics go beyond the individual. In addition to the classic and well-known ethical problems related, for instance, to random controlled trials of interventions, examples of such problems include:

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- how do we take into account the different values that different cultures give to confidentiality?
- how do we define equity in health and how does this affect the way we apply epidemiological findings to populations, for instance in terms of screening or of providing health care facilities?
- how do we ensure the agreement and the informed consent of the community in a society where community representation is vested in the authority of one person rather than in the explicit participation of all?

The choice of target groups for epidemiological studies, the selection of priority health problems, the application of epidemiological research findings, and the use of epidemiology in support of health policies, thus all raise complex and important ethical issues. These issues must be—and are—addressed by practitioners of epidemiology in a variety of social, cultural and economic circumstances. For example, the ethical problems of an industrial society have been considered in a draft "Code of ethics" distributed at the Industrial Epidemiology Forum's Symposium on "ethics in epidemiology" held in Birmingham, Alabama, USA, in June 1989; in a different context, investigators working with isolated Amazonian communities in Brazil are developing guidelines related to the impact of epidemiological work on such communities.

Epidemiology is increasingly recognized as a tool in support of health policy and strategy development. At all levels, whether for individuals, for communities or for nations, ethical guidelines are needed for the application of epidemiological findings, as much as for epidemiological research in itself. Indeed, care should be taken that such guidelines are not limited to research. For example, honest and fair dissemination of knowledge about outbreaks of disease such as cholera and yellow fever, and about major environmental disasters, is a duty for all Member States. WHO has an equal duty in this respect, even when dissemination of information may entail difficulties for individual Member States. Similarly, action on the part of Member States and of the international community regarding the control of tobacco, alcohol or other risk factors, raises questions regarding the balance of health, social and economic benefits and cost, a balance that must also be considered in the light of ethics.

Finally, the diversity of cultures throughout the world must not be forgotten. At present there is a tendency for research priorities, and for proposals for the application of research, to be dominated by the values of the scientists of industrialized countries. The voices of millions of uneducated and deprived people in urban slums and developing countries are all too rarely heard. An approach to ethics must be promoted which takes into account these unheard voices, with their specific social, cultural and philosophical characteristics, while addressing the common issue of scientific integrity. Ethical approaches must also become better known to those who are being trained in the development, dissemination and application of tools for health care of communities, such as epidemiology. We have to be prepared to address the specific ethical issues presented by new diseases such as AIDS.

These deliberations will help to develop an ethically sound basis for the work of the scientific community and for all those who apply the results of epidemiological studies. However, let me inject a word of caution. Guidelines developed at one conference should not become a permanent straitjacket expected to fit all circumstances and all cultures. The results of these discussions should rather be a foundation for continuing and fruitful dialogue among those who practice and apply the tools of epidemiology. Indeed, discussions on ethics, as with any kind of philosophical discourse, require deep, broad and long-term perspectives of thought. It is my hope that this symposium, and the discussions that will follow it throughout the years, will ensure an increasing and continuous integration of ethical concerns in epidemiological studies and applications. And this will contribute to improving health and equity, while respecting human rights.

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