DATA-SECTIE

# REPORT OF THE COLOGNE CONFERENCE ON EMERGING DATA PROTECTION AND THE SOCIAL SCIENCES NEED FOR ACCESS TO DATA

Held at the Zentralarchiv für empirische Sozialforschung,
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IFDO

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#### Resolutions

In a plenary session the conference unanimously adopted the following three statements

### 1. The Social Scientist's Experience with Data Protection

On the basis of an evaluation of developments in data protection within eleven countries, and taking account of the general tendency for legislative measures to have unintended consequences, the conference expresses grave concern about some of the negative impact of data protection laws, regulations, and practices on the social sciences. While we recognize that it is essential to protect the privacy (integrity) of the individual, there is also a need to know and a need to secure the channels through which, under proper safeguards, a reliable and comprehensive understanding of the life situation of individuals and groups of individuals may be obtained.

In the opinion of the conference the need to know and the need to secure a free flow of information constitute the other side of the issue of protecting the privacy of individuals. To a large extent this other side of the privacy issue has not been given due consideration in the process of enacting and implementing data legislation. The conference would like to draw attention to the fact that such legislation can and has become a vehicle for the protection of the vested interests of particularly resourceful groups and organizations, thus contributing toward an infringement of the fundamental rights of other parts of society. It is recognized that the results of significant social research might jeopardize the interests of some of the groups or individuals about whom data are collected. However, it seems important to be sensitive to the possibility that because of this situation data protection measures can be utilized as a shield behind which socially significant issues are excluded from research.

Furthermore, developments in the field of information processing have resulted in very powerful instruments to control individuals

and society. In most of the countries represented at the conference data protection laws are used by bureaucracies to monopolize the information necessary for the open discussion of public policies. The data flow among government agencies has increased considerably during the last few years, although data protection has in some cases placed restrictions on this flow. However, researchers often find themselves excluded from the information necessary to enable them to contribute to public discussion by presenting independent opinions. This is especially dangerous in a situation where government policies are based increasingly on large data bases, including microdata.

The conference is of the opinion that these issues have significant political implications and are associated with broad and general notions of the free and unrestricted flow of information in society. They should be given thorough political consideration in the future development of data legislation and practices.

The conference has learned that with respect to data protection there are significant differences in the situations of different countries. There are nations that have found an acceptable balance between data protection and access to data for research purposes. On the other hand, there are countries where data flow for research has come nearly to a standstill.

In this situation it is necessary to develop guidelines for a general information policy. A fundamental aim of a modern information policy is to make information gathered by public (and private) institutions more transparent and visible in order to improve democratic control. Within this broader framework, social research must be considered not only as a matter of interest to social scientists, but as part of that system of democratic control.

A first important recognition of these problems at the international level came in 1977, when a group of social scientists and senior administrators of national statistical bureaus discussed the issue and drafted a set of recommendations, which are now known in the international social scientific community as the Bellagio Principles. We endorse these principles. We also hope

that the pattern set by the Bellagio conference of joint discussion of common problems between social scientists and governmental officers at all levels will be continued.

In this perspective, the distinction between statistical and administrative data should not be used to make the latter less accessible to researchers. Access to administrative data for scientific purposes should be regulated according to the principle of functional separation of research and administrative data incorporated also in the Bellagio Principles.

The conference wishes to point to the high value placed on freedom of the press. The social science community might be in a better position to improve its services to society if its freedom and rights to do research were secured through similar principles, including the obligation to protect the sources of information.

# 2. Preservation and accessibility

In addition to these general principles the conference recognized other points of interest for the international development of social research. In particular it recommended:

- a) that the data relevant to scientific investigations on human affairs should be preserved in readily usable forms;
- that with the sole limits of protection of privacy and confidentiality recognized in the first part of this statement, research data should be openly accessible to social researchers and the general public of <u>all</u> nations;
- c) that governments should work to eliminate barriers to general access to research data and should take appropriate action to facilitate their use under the principles established by the United Nations charter and incorporated in UNESCO.

# 3. Codes of Conduct

Finally the conference supported the following recommendations toward the adoption of codes of conduct by social researchers:

Social scientists collect information from and about individuals for research purposes. In doing so they have traditionally followed certain standards of behavior: social research is conducted at all times so that no harm should come to individuals while being subjects of research.

The current concern to better protect the privacy of individuals makes it necessary to increase awareness of differences between administrative and research uses of information.

To make this point better understood by the public, covernments and researchers, it is recommended that in addition to the existing codes of ethics in various disciplines, codes of conduct should be developed for each research methodology. These can make explicit the rules that are already respected by the professional researcher. Thus, by common practice in survey research, the anonymity of respondents, their right to be informed about the purpose of a study, their right to refuse cooperation at each stage of an investigation, and their right to know the identity of the researchers have been respected.

The practical ground rules for the responsible research use of personal data will differ with the research method. Each professional specialty should be asked to make its practitioners fully aware of the range of alternative techniques available to implement codes of conduct. For survey research, as an example, such alternatives include randomized response methods, insulated data banks, and appropriate levels of aggregation.

Codes of conduct should have sanctions so that the public can be assured that such codes of conduct are more than mere declarations.

# The Bellagio Principles

- 1. National statistical offices should provide researchers both inside and outside government with the broadest practicable access to information within the bounds of accepted notions of privacy and legal requirements to preserve confidentiality.
- 2. Legal and social constraints on the dissemination of microdata are appropriate when they reflect the interests of respondents and the general public in an equitable manner. These constraints should be re-examined when they result in the protection of vested interests, or the failure to disseminate information for statistical and research purposes (i.e., without direct consequences for a specific individual).
- All copies of government data collected or used for statistical purposes should be rendered immune from compulsory legal process by statute.
- 4. In making data available to researchers national statistical offices should provide some means to ensure that decisions on selective access are subject to independent review and appeals.
- 5. The distinction between a research file, in the sense of a statistical record (as defined in the 1977 report of the U.S. Privacy Protection Study Commission), and other micro files is fundamental in discussions of privacy and dissemination of microdata. All dissemination of government microdata discussed in connection with the Bellagio Principles is assumed to be a transfer of data to research files for use exclusively for research and statistical purposes.
- 6. There are valid and socially-significant fields of research for which access to microdata is indispensible. Statistical agencies are one of the prime sources of government microdata.
- 7. Public use samples of anonymized individual data are one of the most useful ways of disseminating microdata for research and statistical purposes.
- 8. Techniques now exist that permit preparation of public use samples of value for research purposes within the constraints imposed by the need for confidentiality. Countries with strict statutes on confidentiality have prepared public use samples.
- 9. There are legitime research purposes requiring the use of individual data for which public use samples are inadequate.

- 10. There are legitimate research uses which require the utilization of identifiable data within the framework of concern for confidentiality.
- 11. Other techniques of extending to approved research the same rights and obligations of access enjoyed by officers of the government agency need to be considered in terms of better access.
- 12. There is considerable potential for development of more economical and responsive customized-user services, such as 1) record linkage under the protection of the statistical office, 2) special tabulations, 3) public use samples for special purposes. Such services must often involve some form of cost recovery.
- 13. Some research and statistical activities require the linking of individual data for research and statistical purposes. The methods that have been developed to permit record linkage without violating law or social custom regarding privacy should be used whenever possible.
- 14. Professional or national organizations should have codes of ethics for their disciplines concerning the utilization of individual data for research and statistical purposes. Such ethical codes should furnish mutually agreeable standards of behavior governing relations between providers and users of governmental data.
- 15. Users of microdata should be required to sign written undertakings for the protection of confidentiality.
- 16. Considerable efforts should be made to explain to the general public the procedures in force for the protection of the confidentiality of microdata collected and disseminated for research and statistical purposes.
- 17. The right of privacy is evolving rather than static, and closely related to how statistics and research are perceived. Therefore, statisticians and researchers have a responsibility to contribute to policy and legal definitions of privacy.
- 18. Public concern about privacy and confidentiality in the collection and utilization of individual data can be addressed in part as follows:
  - (1) voluntary data collection, whenever practicable;
  - (2) advanced general notice to respondents and informed consent, whenever practicable;
  - (3) provisions for public knowledge of data uses;
  - (4) public education on the distinction between administrative and research uses of information.

excerpted from David H. Flaherty's report in: Statistical Reporter, No. 78-8, May 1978