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## Issues of Privacy and Access

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by Per Nielsen<sup>1</sup>

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### Early academic reactions to privacy and access regulations

#### The IFDO resolutions, August 1978

For a few years in the mid-seventies, members of the international social science community could study the Hessian and the Swedish data legislation practices whilst preparing the viewpoints for which they found it necessary to fight on their national home ground before the enactment of similar privacy legislation. To member institutions of the newly established International Federation of Data Organizations (IFDO), the issues of privacy and access were of central importance, not just as an academic field of study, but as central issues that might

represent a threat to the survival of the data organizations - and to a certain extent even of quantitative social research.

Consequently, in August of 1978, IFDO sponsored an International Conference on Emerging Data Protection and the Social Sciences' Need for Access to Data. At this conference, which was hosted by the most experienced and biggest European Data Archive, the Zentralarchiv in Cologne, comparative national status reports were presented from 10 countries. The national reports were sent to the organizers who collected them in a volume of proceedings that was a tangible point of departure for the discussions at the 3-day conference.

The participants invited to the Cologne Conference unanimously adopted three IFDO Resolutions which served the purpose of drawing attention to as many aspects and consequences of data legislation as possible. The IFDO Resolutions are appended to this note as one of the first, outspoken, academic reactions to privacy and access regulations. They are included in the same form as that in which they were presented to the Danish public in the Danish Data Archives (DDA) newsletter<sup>2</sup>.

#### The Bellagio Principles, 1977

One year prior to the IFDO Conference, a group of social scientists and senior administrators at national statistical bureaux had discussed access to statistical data in Bellagio, Italy. From this event, 18 so-called Bellagio Principles were circulated in the social science community. These principles were considered important because they represented a first compromise between social scientists on the one hand and senior statistics administrators on the other.

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<sup>1</sup>Presented at IASSIST/IFDO International Conference May 1985, Amsterdam.

<sup>2</sup> DDA-nyt 9:12-14, December 1978.

In an explicit statement, the IFDO Conference endorsed the Bellagio Principles, which are reproduced below – again in the same form as that in which they were presented to the Danish public in the DDA newsletter<sup>3</sup>.

#### **The European Science Foundation statement, 1979–1980**

In 1979, a working group of invited specialists in the social sciences, the medical sciences, and administrators from data inspection authorities, tried to reach agreement on a statement which was going to be subject to approval by the assembly of the ESF. During the working group meetings, I felt a peculiar distrust between each group and the other two. The medical experts asserted that their data-handling procedures were safe and felt that it was in the interests of patients (i.e. the public) to supply necessary information to their doctors – without too much interference from the data inspection authority; on the other hand, the medical experts were sceptical about some of the data collection and handling procedures applied by social scientists! The experts with a social science background tended to hold that their own rationale for data collection, as well as their applied data handling routines, were less dangerous to the public than most of the data collection ventures within medical science. And the data inspection authorities felt that both medical and social science projects involving confidential data should be rather rigidly controlled.

In addition to these disciplinary variations in attitudes, the national differences were more outspoken in the ESF working group than they had been in either Bellagio (where Canada, US, UK, West Germany and Sweden were represented by scientists and statisticians) or in Cologne in which about a dozen countries were involved. Furthermore, it took more than a year to reach agreement on the wording of the

final text. After reworking the text as adopted at the conference, a slightly rephrased version was accepted by the ESF Assembly. It is this revised (official) version of the ESF Statement which is appended to this paper.

#### **Reasons behind the diversification in attitudes**

I think it is fair to say that three or four major factors caused the change in attitudes to the issues of privacy and access during the last half decade of the seventies – from consensus to a more diversified set of attitudes. First, the various groups of agents became more aware of their group interests in the course of the data legislation process as the latter proceeded in more and more countries. Second, the discussions moved from a level of soft statements towards one of juridical phraseology in sections and subsections. Third, the differences in existing legal conditions between countries (e.g. in such areas as freedom of information) as well as practical set-up (e.g. a tradition for codes of ethics) implied associated differences in the new legislation and in its actual implementation.

This indicates that there is still a lot of research to be done in terms of comparing the conditions for quantitative research between countries as well as following the trend over time within a single country – as practices are defined and acts are amended.

As can be expected, substantial interest is devoted to this issue among social science data "pushers" and "addicts". Since 1977, there has hardly been a conference of any size or generality which has not had issues of privacy and access on its agenda.

#### **Concluding remarks and recommendations**

As a convener of the IFDO/IASSIST 1985 Conference session on Issues of Privacy and Access, I thought that it might be useful to reprint some of these early deliberations, in

<sup>3</sup> DDA-nyt 9:14–16, December 1978.

order to facilitate discussion along the following lines: what new issues (if any) have entered the debate in recent years, and what is the present-day situation, compared to expectations 5 or 10 years ago.

Finally, I should very much like to see a repetition of the 1978 IFDO conference. Now that most countries have actually been living with enacted privacy bills, a new systematic comparison across countries would prove useful.

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## IFDO

### International conference on emerging data protection and the social sciences' need for access to data

#### ■ Resolutions

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

#### Social scientists' experiences with data protection.

On the basis of 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 the 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 the 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 source of information.

### 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:

- 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 all nations;
- 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.

### 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 behaviour: 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, governments 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.

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### The Bellagio Principles

Excerpted from David H. Flaherty's report<sup>4</sup>.

- 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).
- 3 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

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<sup>4</sup> David H. Flaherty, Final report of the Bellagio conference on privacy, confidentiality, and the use of government microdata for research and statistical purposes. Statistical reporter 78-8:274-279, May 1978.

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 indispensable. 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 legitimate 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 sample 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 behaviour 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:
  - a. voluntary data collection, whenever practicable,
  - b. advanced general notice to respondents and informed consent, whenever practicable,
  - c. provisions for public knowledge of data

uses,

- d. public education on the distinction between administrative and research uses of information.

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### EFS's statement on 'privacy'

Statement concerning the protection of privacy and the use of personal data for research (adopted by the Assembly of the ESF on 12 November 1980) <sup>5</sup>

#### Preamble

The necessity of safeguarding the individual against misuse of his personal data has been repeatedly emphasized, in the last few years, at both the national and the international level. This has been particularly the case in the countries with organizations which are affiliated to the ESF. In Austria, Portugal and Spain data protection is explicitly referred to in the constitution. Specific legislation already exists in Austria, Denmark, France, the Federal Republic of Germany, Norway and Sweden. Draft laws are under consideration in Belgium, the Netherlands and Switzerland, while an official report on the issue has been prepared in the United Kingdom.

There has also been considerable concern with these matters at the international level. The Council of Europe has recently elaborated a Convention for the Protection of Individuals with Regards to Automatic Processing of Personal Data, while the OECD has prepared a series of guidelines concerning the protection of privacy and the movement of personal data

across frontiers. Mention should also be made of the discussions going on within the Commission of the European Communities about a possible directive and of the enquiry carried out by the European Parliament which led to a resolution calling for immediate action.

However, the implementation of data protection laws has led, in an increasing number of cases, to serious restrictions on access to personal data for research purposes. For example, problems connected with the collection and evaluation of information by means of questionnaires, access to information held by public authorities, particularly statistical offices, and the destruction of personal data by such authorities once the purposes for which they were collected have been fulfilled, have been creating considerable concern amongst the scientific community. This led to the drawing up of the Bellagio Principles in August 1977<sup>6</sup> and to an international conference on emerging data protection and the social sciences' need for access to data which was held in Cologne in August 1978, sponsored by the International Federation of Data Organizations (IFDO). These problems were also discussed at the 10th Colloquy on European Law organized by the Council of Europe at Liege in September 1980.

The ESF fully endorses the necessity of protecting the privacy of the individual. It feels, however, that the attention of the legislators and international bodies concerned should drawn be to the researchers' case for special conditions for the use of personal data. These should ensure, under proper controls,

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<sup>6</sup>Contained in the Final Report of the Bellagio Conference on Privacy, Confidentiality, and the use of Government Microdata for Research and Statistical Purposes, which was a meeting of representatives of the central statistical agencies of Canada, the Federal Republic of Germany, Sweden, the United Kingdom and the United States held at the Rockefeller Foundation Bellagio Study and Conference Center in Italy, 16-20 August 1977.

<sup>5</sup> DDA-nyt 18:9-13, sommer 1981.

access to such data when it is needed for specific research purposes. Accordingly, a group of experts under the chairmanship of Professor S. Simitis, Professor of Civil and Labor Law at the University of Frankfurt and Data Protection Commissioner of the State of Hesse in the Federal Republic of Germany, was set up to draft such a statement. After full discussion and revision within the ESF the following principles and guidelines were adopted by the ESF Assembly at its meeting in November 1980. They are put forward to ensure both the protection of personal data and the necessary access to such data for research purposes.

J. Goormaghtigh  
 Secretary General  
 Strasbourg  
 13 November 1980

**Basic principles**

- 'Personal data' are, in the context of this document and in accordance with the definition to be found in the Council of Europe's Convention for the Protection of Individuals with Regard to Automatic Processing of Personal Data and also adopted by the OECD, any information relating to an identified or identifiable individual.
- Data protection legislation must, in order to fulfill its task, which is to guarantee the respect of privacy, cover all uses of personal data and therefore include its use for research purposes.
- Professional codes of ethics are a complement to legislative measures safeguarding the respect of privacy. The scientific communities concerned should encourage the development of such codes, within the framework of the rules established by the legislator, in order to take into account the specific needs of the

different disciplines.

- Freedom of research presupposes the broadest possible access to information. Legislation should, therefore, besides specifying the conditions under which personal data may be used for research, ensure access to the information needed.
- In order to ensure the respect of privacy, research should, wherever possible, be undertaken with anonymized data, following already accepted practices.
- Scientific and professional organizations, together with public authorities, should promote further development of techniques and procedures to secure anonymity. Anonymity should be considered as given, whenever the individual can only be identified with an unreasonable amount of time, cost and manpower (*de facto* anonymity).

**Guidelines**

- Any use of personal data for research purposes, irrespective of the aims for which they were or are to be collected, presupposes either the explicit permission of the legislator or informed consent unless the individuals concerned are not identifiable by the receivers.
- There is informed consent when the individuals concerned have been clearly informed:
  - a. that the provision of data is voluntary and that a refusal to comply will have no adverse consequences on them;
  - b. of the purposes and nature of the research project;
  - c. by and for whom the data are being



collected;

- d. that the data collected will not be used for any other purpose than research.
  - With the approval of the data protection authority, or its equivalent, informed consent is not required in cases where the nature of the research project is such that:
    - a. the informed consent of the individual would invalidate important objectives of research;
    - b. informed consent could cause mental or physical distress to the individual concerned.
  - For the sole purpose of selecting samples for research involving population-based surveys, legislation or other legally acknowledged procedures should permit the use of data concerning name, address, date of birth, sex and the occupation of individuals collected by state agencies for non-research purposes.
  - Personal data obtained for research should not be used for any other purpose but research.
  - In particular, personal data obtained for research purposes should not be used to make any decision or take any action directly affecting the individual except within the context of research or with the specific authorization of the individual concerned.
  - Whenever personal data are used for research, they should not be published in identifiable form unless the individuals concerned have given their consent.
  - In the case of personal data used for research, the individual's right to obtain

confirmation whether or not data pertaining to him are maintained, to challenge data relating to him and to have data erased, rectified, completed or amended should be limited to other research projects where it is intended that the data be used in an identifiable form.

- The leaders of research projects using personal data should be responsible for ensuring that the necessary technical and organizational measures are taken in order to guarantee the confidentiality and security of the data and for keeping these measures under review in accordance with the latest scientific and technical developments.
- Once the specific research purpose for which personal data have been collected has been achieved, these data should be depersonalized and the necessary measures (e.g. the deposit of identifying code numbers with a central research data archive) should be taken for their secure storage.
- The decision to destroy personal data held by public authorities should only be taken after consideration of their possible future use for research and after consultation with the central data archive or a similar organization.