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1. Introduction

About ten years ago I served on our Association's ad hoc Committee on Privacy and Confidentiality (1977) which considered many issues involved with the collection and transfer of data. Several of us disagreed with the practice of linking an individual's data from several sources (usually a survey and the IRS or Social Security records) without the respondents' consent or knowledge because it implies that the government statisticians were not open and honest with the respondents to the survey. We quoted the following passage from the Stanley vs. Illinois decision of the U.S. Supreme Court

The Constitution recognizes higher values than speed and efficiency. Indeed, one might fairly say of the Bill of Rights in general, and the Due Process Clause in particular, that they were designed to protect the fragile values of a vulnerable citizenry from the overbearing concern for efficiency and efficacy that may characterize praiseworthy government officials no less and perhaps more, than mediocre ones.

to emphasize that while we understood the desire of the government bureaucracy to obtain accurate data, the lack of proper informed consent of respondents is contrary to the fundamental principles of liberty and freedom as well as basic moral values that civilized societies have cherished for centuries.

During the last ten years, the fundamental principles of the nation have not changed (e.g., the Court in I.N.S. v. Chadha 103 S.Ct. 2764 (1983) noted

The choices we discern as having been made in the Constitutional Convention impose burdens on governmental processes that often seem clumsy, inefficient, even unworkable, but those hard choices were consciously made by men who had lived under a form of government that permitted arbitrary governmental acts to go unchecked. There is no support in the Constitution or decisions of this Court for the proposition that the cumbersomeness and delays often encountered in complying with explicit constitutional

standards may be avoided, either by the Congress or by the President.

the moral teachings have not changed, the principle of informed consent in medical research has become more accepted and codes of ethical conduct for research have been developed (e.g., The American Psych. Ass'n. and recently, the Int'l Stat. Inst.). However, the statistical agencies' practice of creating data systems without clearly informing the individuals whose data is in the file about the entire content of their record, thereby creating a surreptitiously assembled data (SAD) system, grew unabated (see Boruch and Stromsdorfer, 1986, for the increased use of administrative records etc).

In this paper we start with an example illustrating the main issue. Then we proceed to provide further background on the ethics of research, especially in medicine, and describe how the conduct of some government studies may have been in conflict with basic ethical principles.

2. Basic Principles Applied to a Realistic Situation

In addition to the fact that our schools teach the importance of "checks and balances" in our government since they protect the citizens from the concentration of power in the hands of a few, there are several principles of ethical behavior which underly proper respect for the dignity of humankind. Perhaps the best known is the "golden rule." "Do unto others as you would have them do unto you." In addition, we teach our children that: One should tell the truth and one should not tell a lie, and two wrongs do not make a right.

Let us compare the behavior of a typical honest citizen with that of the government bureaucracy in the following scenario.

The citizen (you) had an opportunity to earn some extra money on a second job as a consultant. Although your boss tends to be jealous when his or her underlings receive such opportunities, you accept the job and earn \$5,000. Your client makes a mistake on the 1099 form they send to IRS and reports that you earned \$1,000. When you fill out your tax return you are faced with a moral dilemma:

- a) Should you report the total amount you earned?
- b) What would the government like you to do?
- c) What fraction of the nation's citizens do you think would answer (b)

with "The gov't would like you to use the 1099 form information. Only if and when the IRS questioned you should you tell the whole story.

You report the whole \$5,000, deducting appropriate expenses (perhaps giving yourself the benefit of the doubt in determining whether some lunches were for business or pleasure).

Shortly after you are asked to participate in a voluntary Census survey to obtain information on the state of the economy. At the beginning of the survey you are asked to provide your SSN before being asked the earnings questions (sometimes, one is in a survey for several months before the sensitive income questions are asked). When you respond to the income questions you decline to answer the question concerning supplementary jobs. You prefer that your boss isn't even reminded of this topic in a subsequent report or newspaper article discussing the survey's findings.

What does the gov't do? Your survey form is "enhanced" with detailed data on your sources of income from the IRS and perhaps other "administrative records." You are not told about the possibility of data linkage with your tax return in the Census Bureau's covering letter.

Let me ask the reader, who is in closer compliance with the "golden rule", the citizen (you) or the gov't. (IRS and Census)?

I should note that if and only if a respondent specifically asks why the SSN is being requested by the interviewer, they are read the following statement

The data from this survey will be used for planning and research purposes by numerous governmental agencies and other organizations. It is necessary, therefore, that the Bureau of the Census evaluate the accuracy and consistency of the data. One of the ways that may be used to evaluate the data is by adding information from administrative records to the survey data. This procedure will help the Census Bureau avoid asking questions for which data is already available, and help us to ensure the completeness of the survey results. The information we obtain from the Social Security Administration and other governmental agencies will be protected from unauthorized use just as the survey responses are protected. (While we can use SSN to look at records of other agencies, other agencies cannot use the SSN to look at the data respondents have supplied Census.) The Social Security

number is requested to aid in this evaluation of the data and will not be used for any other purpose.

The statement is accompanied by the following instruction to the interviewer:

Become very familiar with the above explanation of why the Social Security number is needed. Offer it immediately, correctly, and clearly to any respondent who asks why you want to know his/her Social Security number. If the respondent is reluctant to give the information in spite of your explanation, do not press the matter. Check the "Refused" box in Item 33b. If the person simply does not know the number, check the "Don't know" box and mark the Reminder Card. When you obtain the number, record it in Item 33a and erase the entry in 33b.

While the above answers and instructions are an improvement over past practices, we emphasize that an explicit statement about a linkage to tax return (IRS) data is not even given to those who inquire about the SSN. Indeed, neither tax returns nor the IRS is mentioned in the suggested answer. Please contrast the practices of the statistical agencies with the answers you gave to questions (b) and (c). Of course, these agencies desire the citizens to be cooperative, devote their time to answer the survey accurately, and be totally honest and report their full earnings.

The above example is quite realistic. Indeed, a study of methods of imputation for missing income data in the CPS carried out at the Census Bureau under the protection of their confidentiality provisions by David, Little, Samhuel and Triest (1986) matched the 1981 CPS supplement to 1980 IRS returns on the basis of the SSN provided to the Census Bureau. One item of information obtained from the IRS was whether or not an individual had self-employment income. The author's note that "use of the IRS to validate CPS income reports will be more representative for population subgroups than for others. Fortunately, matching appears to be relatively complete for persons likely to receive large wages, a source of potential difficulty for imputation methods."

Since the CPS is a voluntary survey, while the IRS not only is mandatory, the severity of the penalties for not filing (Saunders, 1986 a,b, notes that one can be fined up to \$100,000 and sent to jail for three years for failing to file a tax return and Congress has added more penalties in recent years) surely render

it coercive, the authors apparently did not recognize that using the IRS records for the high wage earners who chose not to answer the income questions negated the voluntary character of the survey. Moreover, as we noted in our 1977 dissent, the gov't is treating taxpayers differently than persons who are not required to file tax returns. This appears to be inconsistent with the concept of equal treatment of all citizens which has a basic role in the Declaration of Independence and the Constitution.

Not only were the respondents to the 1981 CPS not told of the IRS match, a footnote in the article states

All work involving the March 1981 supplement to the Current Population Survey (CPS) and the 1980 individual income tax records in the development and subsequent analysis of the matched file was done by employees of the Census Bureau to preserve the confidentiality of the CPS respondents. No one other than Census Bureau employees has access to this file. The only products of this study are statistical tabulations summarizing the results of the analysis.

Notice that nothing is said about what the respondents were told. Since they were not informed of the existence of this SAD file, it is evident that an independent verification of the confidentiality of the file is rendered impossible.

3. Ethical Background and Informed Consent In Medical and Social Research

There is a huge body of literature concerning the ethics of lying and I must say, that in my review of it I could not cover all the major writers. Almost all say that a falsehood should only be available for benefit of the individual who is told it, not for the benefit of others.

There is one school of thought that takes an absolute view, e.g., Kant (1909) states, "To be truthful (honest) in all declarations is therefore a sacred unconditional command of reason, and not to be limited in any moral expediency . . .," Others such as Aquinas and Augustine permit certain lies that intend great good but counsel against all lies, holding them to be unnatural as they are contrary to the purpose of communication. Finally, a more utilitarian or situational view due to Bentham and Hare, recently expounded by Fletcher (1967) and Moutsopoulos (1984) regards moral responsibility as being one's response to situations. Of course, these writers

emphasize that based on the principles of concern for one's fellow human beings, love and justice should form the basis of a moral decision so their analysis of most realworld situations leads to the same ideal behavior as the more absolute viewpoint.

In this century, the view of interpreting moral responsibility as response was started by Martin Buber and expanded by Brunner (1947), Barth (1960), Bonhoeffer (1955) and Niebuhr (1963). As you recall, Buber in I and Thou (2nd ed. 1958) described the I-Thou relationship as a dialogue in which individuals treat one another with dignity and respond to each other's needs. He contrasted this desirable type of relationship with the more prevalent I-IT one where people regard others as subjects for manipulation and do not truly respond to them. Buber realized that a dialogue or encounter required honest communication and that this could not be accomplished unless the participants were honest and open with one another.

It is my view that when the government or any researcher does not inform respondents about what the complete contents of their data file will be or that it will be used for different purposes than they were led to believe, the government is treating its citizens as objects rather than with the dignity they deserve as human beings.

I should mention that there is some disagreement concerning deceptive practices in social science research. Moutsopoulos (1984) who generally is an advocate of informed consent in medical research, allows for an exception in social research. She states "deception in social-behavior research is justified...when there is no risk for the deceived, when the deceived subject will be informed retrospectively and when the outcome of the research would be potentially great for society."

On the other hand, Bok (1983) describes the major ethical issue in intrusive social science research in terms of the propriety of research on the private behavior of individuals without their knowledge or against their will. She states "Of such intrusions one can hardly claim that what is being studied is open for all to see. If it were, why would investigators regard it as necessary to employ surprise, pressure and deceit in order to penetrate what for them is so readily apparent?!" She then goes on to point out that students in sociology or psychology really do not have true choice in their decision to participate in an experiment and that welfare clients have difficulty in distinguishing between the studies they are subjected to and the administrative procedures they must go through.

I hope that most of us agree that the

information we supply to the IRS has been given under pressure and that one has virtually no choice in participating in the Social Security system. Thus, I believe that Bok's (1983, p.280) statement "Research lends no special legitimacy to actions otherwise disrespectful of human beings, unless they have expressly consented thereto" is correct. Bok (1983, p.241) rebuts post study informing of the individual as follows "The determination of what is invasive and what is not obviously differs from person to person, and should therefore be left up to each subject, not to the investigators. No amount of explaining the study design and its aims after it is over can justify the failure to offer subjects such a choice beforehand."

Since it is difficult to make a precise definition of a project or file that had been collected using pressure or deception, we make the operational definition: A Surreptitiously Assembled Data (SAD) system or file as one in which the subjects of the file have not been informed of the full content of the information their individual file will contain or of the purposes for which it will be used before the file is created.

In statistical research, these files are created without the consent of the individual respondents or if they consent to answer some questions they are not informed that other information about them will be added to their file. In social science research, almost any deceptive practice will lead to a SAD file on the subjects of study.

We also recall that informed consent in medicine arose from a history of abuses (Miké, 1982) including, e.g., the government-sponsored Tuskegee syphilis experiment and that the determination that someone else is facing no risk is fraught with difficulty. Typically, gov't agencies have underestimated the magnitude of a risk faced by the citizens. The most famous recent example was NASA's estimate of a 1 in 100,000 chance for an accident on the space shuttle which was severely criticized by Professor Feynman. Indeed, most discussions of the creation of SAD systems by gov't statisticians (Jabine and Scheuren, 1985, Clark and Coffey, 1983) only consider the risk that data about a respondent will be used against him. They ignore the potential harm resulting from stereotyping a class of individuals from the results of a study, the deliberate use of erroneous data (e.g., the recent release by a Congressman of a Federal Reserve Board study on wealth distribution after the FRB noted that an error occurred which exaggerated inequality), and the fact that the creation of SAD systems enables the gov't. to conduct studies with databases not known to the research

community and release only those results favorable to the views advocated by the political group in power. Fortunately, public use files permitting independent re-analysis have been made from some linked data (SAD) sets, but there are instances of research results deliberately being withheld from the public (e.g., the long delay in the release of studies of death and deformity in birds at the Kesterson Refuge due to selenium poisoning was noted in the Sacramento Bee on 3/22/86).

4. Examples of Ethically Undesirable Practices in Government Surveys and Studies

In this section we review a few SAD systems, some of which were noted earlier, (Gastwirth, 1986).

- a. The 1973 CPS-SSA-IRS match linked the March 1973 Current Population Survey (CPS) data with Social Security and tax data. The respondents to the CPS survey, whose primary use is the provision of monthly estimates of employment and unemployment, were not told that their answers to income and earnings questions would be checked against or augmented by SSA and IRS data. Similar CPS-IRS linkages were made in 1981 to evaluate methods of imputation.

This study was one of the early ones. IRS information on income for persons who provided their SSN but did not answer a particular item was linked. In correspondence with Mr. J. Gates of the Census Bureau, he noted that when an item is blank the Bureau does not know whether it was a refusal or the respondent didn't know the answer. In either case, the respondents' permission to obtain the answer from their tax return information was not requested by the Census Bureau or the IRS, nor were the respondents subsequently informed of the merged file.

- b. CPS-IRS and some federal assistance program data mergers were carried out in the pilot study for the Survey on Income and Program Participation (SIPP) sample. Matching of currently collected SIPP survey data with these administrative records for individuals and families is planned. Again, all respondents have not been informed that other data may be combined with the answers they provide on their survey form.

In this survey, respondents are only told about linkage to administrative records

if they ask why their SSN is needed. The fact sheet given all respondents does mention that the data they provide will be combined with other data but it does not explicitly state that individual records will be linked. (This interpretation was shown to Mr. J. Gates of the U. S. Bureau of the Census who kindly confirmed it.)

- c. The Internal Revenue Service (IRS) is linking estate tax return data with the tax returns of the heirs to study wealth accumulation by families.

While estate tax data may be used for administrative purposes, e.g., checking to see that recipients of sizeable inheritances report more investment income in future years, it is not clear to this author that these families should be followed for research purposes without their consent. Indeed, when the IRS tried to enlist the cooperation of the top 7,000 income recipients in a study to be conducted by the Institute of Survey Research, only about 10% of them agreed.

5. Miscellaneous CPS-Medicare, CPS-IRS Data Linkages.

A number of special studies in 1978 and 1981 linked CPS data to medicare records or IRS return data using the SSN. Statisticians I contacted at the Census Bureau wrote me, "You were right, there was no mention of our using the data for matching", and "Note, no mention is made of an IRS match."

The unifying themes in these examples are:

- 1) The respondents were not clearly informed of the total contents of their data file,
- 2) Data collected under penalties far stronger than would be applicable to persons refusing to answer a mandatory survey form were used for research purposes without the consent or knowledge of the individuals to whom the data pertains, and
- 3) The subjects of the file were not informed after the data-merge was carried out that it had taken place.

Thus, the agencies' statistical practices don't even satisfy Moutsopoulos's exception for deceptive social research. Even Scheuren (1986) of the IRS who is supportive of current practices when he writes (p.167) "In any case, it is time to stop treating matching as a necessary but dirty business, isolated from other parts of statistical theory and practice" also notes (p.165) in his discussion of the Health Interview Survey (HIS)

"When the social security number question was added to

the HIS a few years ago it was largely for matching to the National Death Index. Great care initially was given to securing informed consent from respondents before obtaining the information. This approach proved tedious and expensive. Now the social security number question is simply asked without much explanation; and, only if requested, are reasons given for why the information needs to be obtained. Response rates are quite high, about 90%, and it appears that the HIS may constitute a major vehicle for a successful data linkage approach to studying aging."

Thus, the gov't. agencies are aware that respondents are not being properly informed.

Conclusion

The purpose of this paper was not to criticize any individual statistician who has been involved with a SAD system or a study using deceptive practices. Since the mid-1970's I have endeavored to focus the attention of our profession on these dubious practices before we lose the confidence of the nation's citizens. Both we and the public have benefited greatly from research based on sound statistical practice. In the 1940's the efficacy of the Salk vaccine against polio was established by a large scale clinical trial. More recently, the link between Reye's syndrome, a rare but very serious illness affecting children and teenagers, and aspirin use was established by using modern statistical techniques such as logistic regression to analyze carefully gathered case-control data. A sizable part of the 50% decline in the number of Reyes cases from 1984 to 1985 probably is due to the publicity which accompanied the announcement of the findings of the CDC study in January 1985.

As I noted in my comment to the Duncan-Lambert paper (Gastwirth, 1986), the public has been quite willing to share sensitive data with us for sound research that will benefit society. Furthermore, they will allow us to obtain data from other sources if we ask them and explain the importance of the project. In their review of the benefits of and problems inherent in exact matching, Boruch and Stromsdorfer (1986) note that obtaining respondent consent to disclose and link records for research purposes is an avenue for resolving disclosure and confidentiality problems and that what little empirical research has been done in this area indicates that it is feasible to obtain consent.

Studies in the medical literature indicate that the informed patient is more cooperative and more motivated (Alfidi, 1971). Furthermore, educational aids for informed consent had no effect on the rate at which patients agreed to participate in a randomized clinical trial (Barbour and Blumenkrantz, 1978).

Recently, Horvitz (Personal communication, 1986) documented the satisfactory results obtained in the Research Triangle Institute's National Medical Care Expenditure (NMCE) Study. Each respondent was asked to report on the health coverage of each family member and was asked to authorize the policyholder's (employer) union or insurance company to provide the data on insurance premiums and how they are paid.

All these studies and case reports indicate that researchers will be able to obtain access to administrative records when they explain the purposes of the study to the respondents. Moreover, the fact that the respondent will learn exactly what data will be taken from the administrative file which will probably

- a) limit the amount of data the researcher will request to what is needed for the specific study, and
- b) build in an added safeguard against unauthorized disclosures from the main data base.

The recent OTA report "Electronic Record Systems and Individual Privacy" summarizes a code of fair information practices suggested previously by the U. S. Dept. of HEW. These principles are:

- There must be no personal data record keeping system whose very existence is secret.
- There must be a way for an individual to find out what information about him or her is in a record and how it is used.
- There must be a way for an individual to prevent information about him or her that was obtained for one purpose from being used or made available for other purposes without his or her consent.
- There must be a way for an individual to correct or amend a record of identifiable information about him or her.
- Any organization creating, maintaining, using or disseminating records of identifiable personal data must assure the reliability of the data for their intended use and must take precautions to prevent misuse of the data.

Notice that SAD systems and the lack of full disclosure by the gov't to the data provider are contrary to the spirit, if not the letter of the first three principles.

The main arguments for the continued creation of SAD systems appear to be

- 1) the risk to individuals is very small, while the administrative convenience is very big and the gain in knowledge is potentially great,
- 2) the individual citizens will not be able to understand the benefits so we cannot "explain" these benefits to them.

I hope the previous discussion convinces you that administrative convenience should be a minor consideration in a democracy. More importantly, it is not our right to decide the risks another individual should take, especially as the research benefits from SAD systems have not been demonstrated to be superior to results obtained by honest-open methods.

The second statement also is paternalistic. Judge Bazelon (1981) in an article concerning risk assessments and scientific uncertainty noted that "the genius of our system is its checks on centers of accumulated power. Nothing but full disclosure can guarantee that the regulators or the new guild of risk assessors will not become the new tyrants. So long as we remain a democracy, the judgement of the people must prevail. As Thomas Jefferson said,

"If we think them not enlightened enough to exercise their wholesome discretion; the remedy is not to take it from them but to inform their discretion."

I would hope that the view that the bureaucracy knows what is in a person's interests better than they do was finally exploded before the eyes of the world on January 28, 1986. I hope all of us can agree that the Challenger 7 crew should have been told that there were serious engineering questions about the reliability of the O-rings in cold weather and that both the Morton-Thiokol and Rockwell engineers had serious doubts about the safety of the shuttle in the cold. I cannot tell you what Commander Scobee and his distinguished crew would have decided but at least it would have been their decision and not NASA's.

Since the risk of harm to individuals from statistical files is undoubtedly less than the risk due to release of medical, insurance, and credit card files, one may question why we should concern ourselves with the problem. The answer is that the concepts of full disclosure, fair information practices and the prohibition of SAD systems and data transfers should apply to all data systems, ours included. As Albury (1983) notes,

Science still provides us with the best access we know of to reliable knowledge about the world, and for this it deserves our support. But its claims to a special status, as a model of institutionalized honesty and critical rigour, cannot be accepted at face value.

Indeed, Barnes (1986) reports that an advisory panel on AIDS Antibody Testing recommended against the current practice of keeping a register of persons who tested positively for AIDS on the ELISA screening test, but not in the confirmatory Western Blot test without informing the individual. She quotes the report "We believe that it is inappropriate to enter a person's identity into such a registry without his knowledge and without giving him the personal advantage of sharing that knowledge and its meaning." The argument that statistical research should be given special status within science is specious at best, especially in light of the recent alleged leak of GNP data from the Bureau of Economic Analysis. It is our duty to end deceptive practices in our profession and to totally reject the view that matching (without the knowledge or consent of the subjects of the file) is necessary for good statistical practice. As this year is the first time Martin Luther King's birthday is celebrated as a national holiday, we recall his famous statement:

An injustice anywhere is a threat to justice everywhere.

As our part in the path of our nation's continued progress towards a more just society*, we must end the unfairness inherent in the deliberately incomplete and inadequate information told respondents of surveys, the creation of SAD systems, the suppression of results of research studies, and we should ensure the availability of the underlying data of studies used in policy-making for independent reanalyses. Ironically, by not allowing massive files on individuals to be created without their knowledge, we will be insuring the continued availability of microdata for independent analysis as the vast majority of individual respondents will remain unidentifiable.

* Although these comments emphasize faults in the ethical behavior of our government agencies, we must remember how much more open President Reagan's response to the shuttle disaster was than the original response of the Soviets to the serious radiation explosion at Chernobyl. Indeed, in his speech on January 28, 1986, President Reagan, when

he appointed an independent Commission to conduct a full-scale inquiry, said "I've always had great faith in and respect for our space program, and what happened today does nothing to diminish it. We don't hide our space program. We don't keep secrets and cover things up. We do it all up front and in public. That's the way freedom is and we wouldn't change it for a minute." (Taken from the text reported in the Sacramento Bee, p.A6, 1/29/86.)

Note: It is a pleasure to thank several gov't. statisticians who provided the author with information and documentation used above. Mr. J. Gates of the Census sent me a list of 13 merged projects carried out since the early 1970's. Seven of these used some information from the IRS and he confirmed that the individuals were not routinely notified of the linked file. Dr. A. Young of the BEA kindly provided me with a copy of the Inspector General's Report concerning the alleged leak of GNP data.

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