Transcript of Proceedings

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

SECRETARY'S ADVISORY COMMITTEE

on

AUTOMATED PERSONAL DATA SYSTEMS

Bethesda, Maryland

Wednesday, 26 July 1972

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NATION-WIDE COVERAGE
DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

SECRETARY'S ADVISORY COMMITTEE

on

AUTOMATED PERSONAL DATA SYSTEMS

Fogarty International Center
Building 16
NIH
Bethesda, Maryland

Wednesday, July 26, 1972
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MS. GROMMERS: By now, I think we all talked about this but I want to talk a little bit about it briefly and we have also got a solution to the problem probably. That's why we asked our panelists to wait a minute.

Several people have come up to me on the Committee saying that our method has been maybe a little too harsh. On the other hand, it is terribly, terribly important to what we are trying to do and that the panelists suddenly see for themselves what, on the other side, they have been doing. So I have been trying to get all of your ideas at an informal level about what we can do about this -- can you all hear me? because I think it would be very bad if we suddenly started being very distant and formal and not getting emotional about some of the things we are emotional about.

We have to communicate the importance and that is the only way to do it and, yet, for example, Mr. Small said to me later, "We thought that we were invited here as panelists and we found out we were on trial."

Now, what we have to do is somehow soften just the tiniest bit of that feeling without taking it all away. The suggestions that have been made to me -- I will pass them on to you for what they are worth, which is a lot -- the first is just to tell you all this so that we all know everybody has been thinking about it, that we have to slow down a little bit but that we must very definitely not stop.
Second is that I think the process we had yester-
day, in the last minute we really were getting a group thing
together so that we can now make our responses somehow relate
to what the other questions have been and moderate the
impression that we are a group, which is terribly important.

Somebody said, "Do you get the idea that it is
like staff is feeding all ideas in to you and they are
defenseless as without counsel?" So we want to modify that
as well.

Joe had a couple of suggestions. Would you like
to make them just quickly? I wanted to get all these ideas.

MR. WEIZENBAUM: I certainly don't think we should
supply them with counsel. I don't get the idea that they are
on trial.

I think that two things are fundamental. One is
that we write up a one page, one and a half page typewritten
document giving the people who appear before us an idea of
what questions we will address ourselves to, what the range
of those questions are and give them some idea of where the
boundaries are.

For example, Mr. Small, yesterday, apparently
thought that we were much more deeply involved in freedom of
the press and things of that kind and then, in fact, we are.
We are certainly interested but that is not our main
objective.
In other words, try to establish for them a contextual framework which should include, I think, a list of the people here, an extremely brief statement as to what their principal interests are. Another thing the witnesses often don't know is essentially who they are talking to. I think that's the main thing.

Secondly, also in the service of providing them with a contextual framework is that perhaps for many of our witnesses, it would be a good idea of the Chairman were to appoint two or three members of the Committee, a different set of two or three, depending on who the witnesses are, to spend about half an hour with them before they actually appear and fill in the context, try and define their anxieties with respect to talking to them and perhaps short-circuiting some of the mistakes they might make in the sense of time wasting.

They may think they are here to say this or that, that they are going to be provided with facts. So I think those two things combined would make it certainly easier for the witnesses and would make it more hospitable for them and more easier for us.

MS. GROMMERS: What we can do is come back to this level later as a panel, but I wanted you all to hear all that and maybe you may have some other ideas.

MR. SIEMILLER: I think that it is very
discourteous though, when they are coming in and when you argue with a witness, you can argue with him, but you accept an answer when you know it is wrong. You are not trying to convince him, you are just picking his brain. I think that is where we get off base.

(Brief recess.)

MS. GROMMERS: Good morning, gentlemen. We are sorry that we have kept you waiting for a brief amount of time here and hope you will forgive us for that. Can you hear me?

We are very happy to have you here with us this morning to discuss the national cancer survey and perhaps to give us some other insights into it that you might have already had from the science staff's preparation.

Doctor Schneiderman, could I ask you to introduce yourself and the other two gentlemen with you.

MR. SCHNEIDERMAN: I am Marvin Schneiderman. I am the Associate Scientific Director of the National Cancer Institute, Demography. Demographer -- I mean, that's not the appropriate title. I am not a demographer. I'm sort of a second-class mathematical statistician, and I think the title demographer was sort of forced upon us. We do do some demography but we do lots of things as you will find out when we talk here.

Doctor Cox is an old friend. I notice she agreed that I was not a demographer.
On my right is Mr. Geller who is head of our Special Survey Section concerned with the third national survey, cancer survey.

On my left is Mr. Weiss, the head of our Data Management Group and is concerned with the setting up of the computer systems that we have used in this particular job that we are doing and, in fact, with all the other things going on in our particular area.

We have a couple of things we would like to give you before we start. Is that permissible?

MS. GROMMERS: Please.

MR. SCHNEIDERMAN: We will give you the handout that we gave to physicians and other people cooperating with us when we first started the third national cancer survey. That is this little blue thing.

It gives a very brief description of what we do, and then we will also give you the first publication from the third national cancer survey, the preliminary report for the data covering the year 1969 which appeared approximately just about a year ago, and these were from the data gathered for the first year of this three-year survey.

Now, let me tell you a little bit of why we are doing this, what the background is and what we hope to accomplish by this rather large data collection system.

The National Cancer Institute has, as you might
guess from my calling this the third national cancer survey, twice before done surveys of the incidence prevalent in mortality from cancer in the United States in certain sample areas of the United States. Each time, we have done this.

The first one was in the late Thirties, 1937, 1938, that time, to tie in with the 1940 census; then ten years later, to tie in with the 1950 census, and then we skipped the 1960 census. We did not do a survey around the 1960 census.

We then did one around the 1970 census. The obvious reason for doing it around the time of the census is to get basic population data upon which we compute the various rates that we are concerned with, particularly rates of incidence.

There are no general sources of data in the United States on the incidence of cancer. There are data on the mortality from cancer. The National Center for Health Statistics publishes these. The most recent publication of the mortality data cover the year 1967. The 1968 data should be published soon.

Why are we concerned with incidence as opposed to mortality? It would seem to me fairly obvious that there are a couple of things that intervene between the incidence of the disease and mortality from the disease.

Obviously, there are questions of treatment. If
our treatments are successful, we will have very little more mortality. Second, you treat incidence cases in a hospital, in the medical facilities. You want to know how many people are ill who then have to be treated, who then use your medical facilities. Therefore, you have to know how many cases there are.

Finally, the changes in incidence that occur are the important things in terms of our recognizing what is going on in our environment, in our society, which are leading to increased or decreased disease -- not changes in mortality which are very largely a measure of medical care or could be a measure of medical care -- but in terms of what is happening to us outside. We do need to know incidence figures.

For example, the incidence of breast cancer in this country has been going up slowly but, nonetheless, has been going up over the last 20 or 30 years; whereas, the mortality has remained relatively constant.

This implies to us two things. There are changes occurring in our way of life, in our society, in our diets perhaps, in age of marriage and the number of children women have which are modifying the incidence of this disease.

While this is going on, there are changes occurring in terms of the quickness with which a woman will come to a physician to have a disease diagnosed and there are changes going on with respect to treatment of the disease so that the
earlier diagnosis largely initiated by the woman herself combined with perhaps somewhat better treatment has kept the mortality of this disease at a relatively constant level in this country; whereas, the incidence is going up.

So in one sense, as a measure of medical care, medical care is getting better in this disease. In another sense, this disease is increasing, and it is, increasingly. We want to know why, so that perhaps we can take some steps, some ways of helping prevent the occurrence of this disease.

Now, obviously, there are certain obvious diseases that you will know about in which action concerning prevention surely would be quite important.

Lung cancer, for example, in which we are convinced that we know the major cause: cigarette smoking.

There are others for which the incidence have been going up quite rapidly for which we haven't the vaguest idea, and I mean that in just those words -- we haven't the vaguest idea of what is going on: cancer of the pancreas, which is now in the process of becoming the third or fourth most important form of cancer in this country and we don't know why. We don't know why the incidence of this disease has gone up so very rapidly over the last 20 years. It is, as I say, coming up as one of the very important diseases.

Things are happening in the other direction, too,
of incidence. Invasive cancer of the uterine cervix, once an extremely important disease of this country, incidence of this disease is going down and going down very nicely. It is going down very steadily and has been going down over a long period of time, going down somewhat more rapidly among blacks than among whites, by the way, over the last decade and a half.

This was a disease that was once considered a disease of black women and not of white women, a little racism in terms of this, and probably not a disease of skin color but of social class. But among blacks, it has been going down more rapidly than it has been among whites. It is a disease that may be in the process of disappearing unless a new sexual revolution starts it up again.

Cancer of the stomach is disappearing in the United States, a disease in which the incidence is going down very rapidly. This is very fortunate because cancer of the stomach is one of the diseases that is almost untreatable. Diagnosis of this disease is almost a signing of the death certificate. Mortality is very high, survival very small.

Our survey covers, as you will see from this little pamphlet, several areas of the country including two whole states and the Commonwealth of Puerto Rico. It covers Iowa, Colorado and the Commonwealth of Puerto Rico. We have done these on Iowa and Colorado in order to cover and get
some information on rural populations. By and large, most of
the work done, cancer studies are done in the vicinity of
large hospitals and so, by and large, you will get urban
information.

There are clear differences between urban and
rural populations and this is a country that still has rural
population. We still have farms and we do need information
on the rural population.

The Commonwealth of Puerto Rico is covered for
the first time. It is quite unlike the rest of the United
States, as you know, in its population composition and quite
unlike the United States in its economic levels.

In our preliminary data from the Commonwealth of
Puerto Rico, we are seeing that Puerto Rico is reflecting
the income of the people there, the way of life there.
There are cancers among people, important cancers in Puerto
Rico that are essentially considerably less important in the
more affluent continental United States.

Cancer of the stomach is an important disease in
Puerto Rico. Cancer of the liver is an important disease in
Puerto Rico. They are considerably less important in the
continental United States.

I think from our data in Puerto Rico, we have
very strong indications of where improvements in the way of
life changes, in economic status, things of that sort will
improve. In other words, reduce the incidence of cancer in Puerto Rico, and then have implications obviously for certain segments of the United States population, segments of low income.

So for that reason, we have included Puerto Rico and the two states involving rural areas.

We have San Francisco which includes a fairly substantial oriental population. San Francisco Bay area also includes one of the large black population in California: the Oakland area.

We have Detroit which is an industrial city, so we can look into problems of industrial carcinogenesis and includes a large black population. Pittsburgh also includes a large black population. We have Birmingham in the southeastern United States and another city in the southeastern United States, again, to see whether we can get regional differences in this country.

There are regional differences and we are trying to find out why they come about, whether by way of life, climate, perhaps genetics. All these things are questions that have to be looked at and have to be settled.

We hope we can find some information, most of this relating to the origin of the disease, most of this hoping to give us clues to look into the origin of the disease so that we might then go out and take preventative measures.
There is very little being done in this country at this time by way of prevention of cancer other than the anti-smoking campaigns and these have been moderately successful. They have not been successful as we have hoped. There are certain portions of the population who are not well reached by these campaigns. White middle-class people are superbly reached by these campaigns. Apparently, the advertising people who have set these up are apparently middle-class white males, and that's why they are doing a great job on it.

There are in the United States roughly 45% of males who consider themselves former smokers. So these campaigns have reached them. Women are not so easily reached by these campaigns, so that it is closer to about 25% of the women who consider themselves former smokers. Some aspects of Women's Lib distress me. This is one of the aspects. Women feel free, freer now to not give up smoking. They are going to demonstrate their independence in some way. I am distressed by, "You've come a long way, Baby" type things. I think Women's Lib is going to help us increase — at least in this case — help us increase lung cancer and I don't think that is a useful thing to do.

We have not reached the black population very well. The proportion of black males who are smokers is substantially higher than white males who are smokers. Lung cancer among
blacks, black males, is substantially higher than lung cancer among white males. This may be a reflection of many things. I suspect it is a reflection of the kinds of jobs these people have, the kinds of environmental exposures they have, the kinds of personal air pollution as well as impersonal exposure; impersonal through the position and personal to where they work and what they do.

Black women have not been well reached. One, because they are women and, two, the appeal is really toward the whites. So these are the kinds of things we hope the data will give us more basis for working toward.

The sample on this, as Mr. Geller has pointed out to me, there are two aspects of this. This is not covering the whole country quite obviously. We are covering about 10% of the population of the United States which, in the cities, in the areas we are covering, in itself is an enormous sample. We are doing it for a period of three years because although we are covering 10% of the population of the United States and cancer is the second most important cause of death in this country, cancer is really a rare disease.

So that as I remarked to Mr. Courtney Justice a little while ago when we were talking about this in children's cancer, it is the most important form or the acute lymphocytic leukemia about which our chemotherapists have done a better job of providing better care than before.
Acute lymphocytic leukemia will affect perhaps a total of 2,000 children in the country this year. This is the stuff you see in the newspaper. The early Christmas party for Jimmy before he dies before Christmas. This is the disease he generally has.

The disease affects only 2,000 people in the course of a year. We are going to find out something about the ideology of this disease, the origin. We are really going to have to get information on more than one year.

Certainly, the other forms of rare diseases that are far fewer than that, we think the rare forms of the disease are the ones most likely to give us information on ideology because it is most likely that these forms of the disease will have only a single ideology. They are rare. Therefore, it is only one thing perhaps, if we are lucky, only one thing that is leading to the disease.

If this is the case, then if we can gather enough cases, maybe we can ferret out what that one thing is and maybe we can prevent that one disease.

So for that reason, the survey will cover -- and this is the first time we are doing this -- the survey will cover three years: 1969, 1970 and 1971. The 1969 data, as I said, have already been published. 1970 data are well now along, are in publishable form or will be in publishable form by October of this year. But I don't think we are planning
to publish these. I think we will now publish the whole set altogether. There doesn't seem to be any good reason to publish another intermediate report now that we have published this one preliminary that you have.

Finally, we are very much concerned about the incidence of cancer in people with different ethnic and genetic stocks. Cancer, this disease, may have -- a big question mark -- may have some genetic components. If the disease has some genetic components, skin color will be a tag to help us identify some of these genetic components. It is also a tag to help us identify social and economic things.

But for this reason, we want to get information on blacks, on Chinese, and, again, that means we will have to gather a lot more data because we are doing 10% of the population. If blacks are 12% or 13% of the total population, you can see how much of a smaller number we've got. We immediately have *together very few cases.* If we are going to look for ideology, we are going to need more than that.

In addition to gathering these data on incidence prevalence and mortality from the disease, we are also attempting for the first time to gather data on the economic impact of the disease and some of the social components of it.

On a 10% sample of the patients identified in this survey with the agreement and approval, *written approval*
of the patient's physician, we are gathering further information in more depth, attempting to give us information on how does the patient eventually get to the physician? How does the patient get into the medical care scheme? How does the patient get into the medical flow of this country? What does the disease cost its patient, its family? What kind of social and economic disruptions and upsets does this lead to?

We have not had -- and Mr. Geller will be able to talk to this point more than I -- we have not had uniform acceptance among the physicians in this country of our requests to interview their patients.

In some parts of the country, the physicians have been quite agreeable and said, "Yes, my patients knows the disease that he has. Is this your interview? That's all right. You may talk with him."

In other sections of the country, the physicians and I think this is an aspect in sociology of practice with American medicine -- other sections of the country, the physician has said, "No, I don't want you to talk to my patient. I don't want you to talk to him and not his family. They don't know what is going on. Don't upset them."

Then quite obviously, don't go and talk to the patient or his family.

We should have publication on some of the preliminary information. We are aiming for October of this
year, and I think we will have, really, the first sort of nationwide comparisons of the costs of this disease and the patterns of achieving medical care that have ever been published. And as I say, our first reports on that will come in October. We are planning for October of this year.

Now, I think I have given you enough by way of background and I think we are amenable to your questions. We will try to evade them, of course.

MS. GROMMERS: Can I ask Doctor Geller, first, to speak to us specifically about the replies and aspects of the forms, just to pinpoint for us what is identified, what is not identified. What use do you make of the identification?

MR. GELLER: Surely. I don't have enough copies of our forms. I didn't know how many people would be on the Committee but I do have five sets of the forms that we use.

MS. GROMMERS: I would like you to pass them around. We'll distribute those so that we can look at them.

MR. GELLER: Well, why don't I give them to you or your staff people.

MS. GROMMERS: We will bring a lot of this out in questions. It is just to orient another question coming in.

MR. GELLER: There are three basic data gathering forms, or forms for gathering the basic data. One is the form used for hospital records where we have our own contractors going into the hospital and abstracting data from medical
Another form is used in abstracting the data from death certificates, from deaths that occur in the area or residents of the area, outside that area. And the third form is information from private practitioners where patients have not been into a medical facility, we ask the doctor to fill in the form.

Each one of these forms has identifying information. It has the patient's name, address, then demographic information: age and sex, race, marital status, things like that.

We use the name and address for two purposes; one for comparing the patients. This is a continuing survey. We get multiple documents on the same individual, and in the field office, they do a preliminary screen of the documents as they come in to make sure it is a new patient; if it is an old patient. We assign the patient number.

So we use the name and address for this purpose.

We also use the name and address in the interview or the sample portion since part of the sample is an interview with the patient, we need the name and address to contact the patient although we could sort of not do this. We could ask the physician when we inquire from him if we could interview the patient. These are the two main reasons why we have the name and address.
As far as confidentiality of the name and address, in the computer files we have separated the name and address from the basic physical data. We have a separate file that has the case number and address. We have a separate file with all of the data.

For the patient interview, I have a copy of the booklet here. The booklet has no identifying information on it at all except the case number. The identifying information comes in on a separate form called the cover sheet and that is held separately from the booklet, so that you then have to have both pieces of paper to identify the patient and the information in the booklet.

At the present time, we do not have the information in the booklet on the computer. It is still in raw data and we are still working with a method of coding it and getting it into the computer.

MR. SCHNEIDERMAN: Let me sort of underline a little of the security aspects and the confidentiality aspect.

In addition to separating the identification information and the data so that when the data are put together there is no individual identification in relation to this, Mr. Steele has prepared for you, as a summary of what we are doing, what looks like a very nice statement, a very good summary of what we are doing. And he includes on that, on page six, some of the security aspects of what we are doing.
Every employee -- and they are not employees of the Federal Government, by the way -- where we are doing this, out in every area in which we are working on these people, are employees either of the Health Department of medical school or university or something of that sort. Those are our contractors. Every employee has to sign a pledge concerning the confidentiality of the data. Every employee is given a little statement as to why these data are so confidential. Cancer is an important disease. It has emotional components. Don't talk to anybody about anything that you see among these records. You may recognize the name of somebody that you know; don't talk to anybody about it. Don't talk to your husband. Don't talk to your wife. And a little statement on this is to why this is of consequence.

We get feedback on this in terms of some of the requests that we get for information. And by the way, I think we would like to have your advice with respect to some of this. We get requests for all kinds of information out of this system ranging from tabulation for a region somebody is concerned with that is going on in his area. "Could you give me a special breakdown and tabulate the same kind of data that is in here? Could you tabulate it for my city?"

The Director of the Michigan Cancer Research Foundation in Detroit asked that. Obviously, we can do that. We have done it. We can identify anyone in any way. We can
get a range for that, which is obviously a reasonable thing for a man in his area who wants to work on his immediate local problems, to request from a lawyer for a patient who was suing her physician concerning what she thought was the improper treatment for her disease, and he wanted the names of all the other people in her area who had the same disease.

Well, quite obviously, we are not going to give it to him. We ask him, "What do you want? We can't give you the names. It is against the law." We may not do this.

Well, he wants to know whether the other people in the area who had had the disease, what forms of treatment they had. This kind of information, we can tell you. This proportionate patients had that treatment. This proportion had that and this proportion had that.

He wanted to know how long they lived. Obviously, we can get you -- not out of this, but other sources, we can get you survival information.

So as I say, we get a great range of requests for information. We do have two Advisory Committees and, in general, they have advised us -- what makes great sense to us no identifying information to go to anybody, no matter what the request is. Two, no raw data to anybody even in the unidentified form, provide tabulations in terms of what the people ask for, because even though you might think you have covered everything in terms of confidentiality, sometimes we
have produced raw data, especially with rare forms of the
disease, you know, there are only three people in the whole
community who have had these diseases, you can then identify
them.

So no raw data. Again, only tabulations. These
are the general rules under which we operate. The material
again, as indicated in Mr. Steele's notes to you, the material
is locked in files, kept in locked files. Where records have
to be sent, they are sent by registered mail or personal
individual messenger.

To our knowledge, so far -- I will cross my eyes,
fingers, legs, et cetera -- to our knowledge, so far, there
has not been one leak, at least none that we have heard of.
Certainly, none that anybody has complained of. "You let
somebody know that my father had cancer of the prostate."
This has not happened to us. We have, to this point, handled
how many records, Ted?

MR. WEISS: Almost 900,000 records. Almost 300,000
cases.

MR. SCHNEIDERMAN: Almost 900,000 records, so we
are rather pleased with what has happened so far.

MR. WEISS: By the way, that was one of our great
concerns at the beginning of the study when we were designing
the data processing system, as to how to prevent this kind of
thing from happening and we have taken some very -- what I thin
are some fairly elaborate procedures to protect the confidentiality of the data in the files.

MS. GROMMERS: Thank you very much. I think we will start with the questions. We want to try to be through with our questions by eleven. We will certainly allow four minutes of questions per person.

Mrs. Cox.

MS. COX: About what size of a group does your policy or rule say that you must have, a group of what size before you release this group data?

MR. SCHNEIDERMAN: We don't have a fixed rule on this.

MS. COX: Well, do you have a feeling on it?

MR. SCHNEIDERMAN: My feeling is that of the order of twelve to fifteen cases and you are not going to identify anybody.

MS. COX: Just how much? You say the cancer patient was only in the overall survey and not in the sample, in the sub-sample but more information --

MR. SCHNEIDERMAN: Yes.

MS. COX: -- is not told? But that --

MR. SCHNEIDERMAN: We don't contact the individual.

MS. COX: You don't contact the individual?

MR. SCHNEIDERMAN: Our data come from physician records, hospital records, death. The individual patient is
not contacted except the one who is in the survey.

MS. COX: Of course, that is fairly general information. That is not going to hurt him. But when you go for the sample, you have got to give some degree of confidentiality.

MR. SCHNEIDERMAN: Yes. And, in fact, if in our agreement with the physician on the sampling, the physician says this patient does not -- "You cannot interview him. He doesn't know his disease and you must not tell him and you must not tell any member of his family," our interviewer is informed of this and asked to work in the fashion where it may limit some questions he can ask.

MR. WEISS: There is a document in the folder which indicates the permission that we do obtain from the physician prior to contacting the patient.

MS. COX: Yes, I saw that.

MR. GELLER: We have to go through this. First, we contact the physician and ask him, "Can we interview the patient?" Or, if not, if the patient is a responsible individual and if they get any resistance at all, the instructions are not to push, and the same thing with the patient if the physician says, "OK. You can interview the patient," they contact the patient and if the patient has any resistance, they back off.

MS. COX: Just one more question on this previous
paper that came to us. You say there is no formal record kept to whom you give the data. Wouldn't that be advisable and a protection?

MR. SCHNEIDERMAN: Yes, I think it would be.

MS. COX: And it would be helpful in comparison on what the different centers are doing, the bulk of that, how much of it you have to give to ---

MR. SCHNEIDERMAN: I think perhaps we can keep just a journal of who asks for what and what was done with it. I think we should do this. We haven't done it ---

MS. COX: So far.

MR. SCHNEIDERMAN: In many ways, we like to operate as much in the open and with as little red tape as possible, and we are sort of treating these data as other data we work with. If you want something, we will tell you if we can.

MS. COX: I don't see why that should be classified as an invasion of personal information, if a research person is getting data from you.

MR. SCHNEIDERMAN: No.

MR. WEISS: Actually, to date, the people who have been receiving information from us are the field offices themselves or the principal investigators within the field offices. They are the only ones who have received back detailed information.
Other individuals or organizations such as the hospitals that contribute, or the physicians that contribute case information to us receive only tabulation data and that is primarily the data we give.

MS. COX: You see, that is very interesting information because the survey people doing the intensive work are trained professional research people and they have to be -- and so they want to see this.

MR. WEISS: I would like to add something here.

MR. SCHNEIDERMAN: Let me break in. I think that is a useful suggestion. We will ask our people to keep this journal record of who asks for what and what we give them.

MR. WEISS: We do have a great deal of information, not in terms of the diversity of the information on a particular case, but the quantity of information, some of it similar information. But there are so many complex aspects and relationships of each piece of data to another that we are really very reluctant to give out to any individual detailed information. They would have to have a very, very large, very complex manual to understand all of the relationships.

What we hope to do at the end of the study is to summarize and create and extract files for investigators, qualified investigators to use, where we will very, very carefully analyze and make decisions concerning the data.
At this particular point in time, most of the information is fairly rough, and we do manage to purify it in order to produce some of the preliminary reports. But it is certainly not something that we feel at this point we can put in the hands of any investigator.

MS. COX: Just one more quick, quick question. This is descriptive information that you are releasing at this stage. Are there plans that you, yourself, have to do analytical or --

MR. SCHNEIDERMANN: Yes.

MS. COX: I think maybe there is a committee working on that right now.

MR. SCHNEIDERMANN: Yes. In fact, we have two preliminary manuscripts on analytical work on the 1969 data already, and there are plans where we are now discussing with the editor of the journal of the National Cancer Institute, plans for producing either a monograph, journal of the National Cancer Institute, a monograph based on those data, or a series of separate papers, sort of sight oriented.

MS. COX: That would be on the three years?

MR. SCHNEIDERMANN: On the whole three-year thing.

MS. COX: One more question. Do you use the same sampling area or the same --

MR. SCHNEIDERMANN: The same sampling area.

MS. COX: So you can make the comparison?
MR. SCHNEIDERMAN: Yes.

MS. GROMMERS: Mr. Davey.

MR. DAVEY: Pass.

MS. GROMMERS: Mr. Gentile.

MR. GENTILE: Yes, I have essentially one question and one comment.

First, my comment is that of many systems we have looked into, I am impressed with some of the things you have done, for instance, policy, impressed with that and I think the committee could benefit by anything that you might have in writing that is procedural so that we might share it with others, in my instance, with my state and other colleagues.

MR. GELLER: I just happen to have a document in my pocket.

MR. SCHNEIDERMAN: Mr. Geller doesn't carry policy books around with him but that is procedural.

MS. GROMMERS: Could we have a copy of that?

MR. SCHNEIDERMAN: Yes.

MR. GENTILE: Would this cover things as quality assurance in the systems design and how you go about getting acceptance from the subject of the file as to what data are contained?

MR. GELLER: It is contained in that. It doesn't go into as much detail, but we do indicate in the manual the levels of confidentiality, what you are supposed to do in
31 contacting a patient and contacting a physician, things like that.

MR. SCHNEIDERMAN: I don't know whether --

MS. COX: You're talking about the machine.

MR. GENTILE: I'm really talking about all the administrative as well as the machine and software. I understand you have limited access of certain journals, as to what files they have access to.

MR. SCHNEIDERMAN: That is right.

MR. WEISS: We have devoted a great deal of time and money to the documentation of the system, the editing criteria, the procedures for validating the data, for correcting information and so forth.

We do have a great deal of documentation available.

MR. GENTILE: This would be very helpful. How do you control your people? I assume you sometimes get new people in your organization.

How do you indoctrinate them? How do you assure that --

MR. SCHNEIDERMAN: We have, in the past, had training sessions, sometimes as long as two weeks; first, for the supervisors for each regional office, then for the sub-personnel within each office working with them in attempts to first, impress them with the confidentiality, then with
the details of the operation.

We have had -- what? -- four of these or three
of these general training sessions, long-term training
sessions to get our people into the frame of mind and to work
with us in terms of what these data mean to us, as well as
what they mean to them.

MR. GELLER: The way that the survey is super­
vised from NCI, we have ten field offices, private contrac­
tors, who are doing the data gathering, and we have an indiv­
didual who is responsible for one or two of these field offi­
ces.

He works quite close with it.

MR. SCHNEIDERMAN: Someone from our staff.

MR. GELLER: Someone from our staff actually goes
out and visits the facility four or five times a year, stays
there or goes with him to the office because ours is a quality
control system.

Any new employees, we go out and abstract with
them to see if they understand what we are trying to do, the
procedures that we are using, the terminology we are using.

So there is quite close contact between the field
offices and headquarters.

MR. GENTILE: One final comment, Madam Chairman.

MS. GROMMERS: Yes.

MR. GENTILE: Another one of the concepts that you
gentlemen -- or two of the concepts that have been discussed in this committee and that you are implementing, number one, you have established a set of two files: the identification that is separate from the case abstract and the data on that individual.

Although it is still under your own control, I think this is a very good thing to point out. Secondly, that you have established this advisory group, which I assume does not report to you folks, that decides on who has access to what data and what can be passed on.

I think these are all positive steps. That's all I have.

MS. GROMMERS: We would appreciate having a copy of any such documentation as you can supply it to us.

Professer Weizenbaum.

MR. WEIZENBAUM: I would just like to follow up for a moment as to what Mr. Gentile just said.

With respect to the separation of name data, the substantive data, have you considered giving the name data to some other -- I'll say -- agency?

I don't mean that in government terms, necessarily, just to increase the safety of that -- that is, simply if you in fact need to go in to the record.

MR. SCHNEIDERMANN: You suggest we would then perhaps go through someone else who knows we are going through
the record?

MR. WEIZENBAUM: Right. And keep an audit on that, I wonder if you considered that.

MR. WEISS: We didn't consider that specific method of keeping confidentiality. We spent a considerable amount of time in the developmental period and we felt that with the steps that we have finally decided upon, for example, the separate files, the locked and storage facilities, separation of our files from other files, the fact that the name and address information never appears on the same report with any other information about the patient, no mention of cancer is ever made anywhere, and we attempt to codify.

We have made extra attempts to codify, in that, normally, in the data processing system we try to simplify the information.

We have attempted to make it more complex so that if anyone happened to find our reports, it would be very difficult for them to understand what was on them other than the people who are specifically trained in its use.

MR. WEIZENBAUM: I take it, when you say codify, you mean in crypt?

MR. SCHNEIDERMAN: In crypt, yes.

MR. WEIZENBAUM: I just want to make a little comment on that point on this business of sequestration. I would suggest, even if it isn't necessary for you to do that
and apparently you have paid very much attention to the
generality of the problem it might nevertheless be a very
good example and a precedent for other persons to do it.

MR. SCHNEIDERMAN: Certainly an intriguing idea.

MR. GELLER: One of the problems we have had is
that we are constantly going back into the files. We are
updating our data every week.

MR. WEIZENBAUM: That would make it a more power-
ful example if you imposed a burden on yourself of confiden-
tiality.

(Laughter)

MR. WEIZENBAUM: But let me, if I may, pursue
that in quite a different line for a moment.

I take it that one of the things you do is to
go to, say, a big hospital and ask to see their records
in order to extract from their records the information you
want.

Now, isn't that true?

Now, in doing that, of course, you see a lot of
records that are not interesting to you and you see some that
are.

I would just like to hear your view as to -- I'll
use the word "propriety" because no other word comes to mind,
that's not really exactly what I mean, that procedure --
you know, looking at it now from the point of view that an
individual patient who goes to the hospital and either --

MR. SCHNEIDERMANN: Why should I see somebody's psychiatric record, for example, if the hospital has psychiatric records?

MR. WEIZENBAUM: I will tell you where I am going and that might help you answer the question.

Taking, for example, that we suspect that the epidemiology of cancer has very little to do with — that it is not infectious and communicable, generally speaking, but again, you are an example and others are an example, you might think of venereal disease, related diseases, and there might even be some instances of cancer where it may become important to trace changes of associations among various patients and so on.

Okay. Now, that begins to be much more complex and sensitive.

Okay. Now, a bunch of researchers, in this instance with a highly legitimate purpose, who are in fact very, very careful with respect to confidentiality and observe the ethics and so on, they will go in and look at records and make certain inferences.

I just wonder what your attitude is of looking at this from the point of view that if the patient who came in to the hospital with implicit or explicit guarantees that his record is not going to be seen the patient is
probably naive with respect to this and probably believes
that the record is going to be seen only by his physician
and possibly one or two other people -- you see, I am
pushing this example thing -- where does one, just like
here, in an attitude on your part in your view, where does
one put justification down, where even though there may be
a legitimate research need and, nevertheless, we have privacy
and confidentiality issues, does research justify everything?

MR. SCHNEIDERMANN: Would you -- well, did you
see the account this morning in this morning's newspaper of --
this is not pleasant -- of what my predecessor did in
Public Health?

MS. GROMMERS: I might mention that, for those
who didn't read it, it is startling.

MR. WEIZENBAUM: I'm sorry. I don't know what
you mean.

MR. SCHNEIDERMANN: I mean, the researches done
at Tuskegee starting in the 1930's on following but not
treating patitnes with syphilis so that one might then look
at their autopsy records to see what a person who dies of
syphilis dies of, what kind of instruction had occurred in
following.

I think this is a dreadful kind of thing and I
do not think research justifies everything.

MR. WEIZENBAUM: I assure you that --
MR. SCHNEIDERMAN: In fact, I was appalled.

MR. WEIZENBAUM: Could you respond to —

MR. SCHNEIDERMAN: Could you talk to it, Harvey, on how we do it in the hospitals and get the data?

MR. GELLER: One of the requirements for contracting with a local agency is to get an opinion from a legal-- either their legal office or state legal office indicating there was no illegality in the hospital providing us with the medical records.

Cancer is recordable in some states and, therefore, the work that is done in the abstracting or the data gathering becomes an arm of the local government.

And in others, the legal opinion was that this was not a breach of confidentiality as far as the patient—hospital relationship.

Now, the usual procedure in a hospital is not for our people to go through the medical records. We have worked with the medical record librarians and with the registrar's secretaries where there is a cancer registry in the hospital, and when they come in, they are usually given a pack of records.

These are the cancer patients that we have in our hospitals.

MR. SCHNEIDERMAN: In other words, the hospital —

MR. GELLER: The hospital pulls the records and
files, the medical records.

We have gone through a process called case finding. We go through the path reports. The pathologist lists the patients he has examined and the diagnoses and this is just by name so you have no address there, going through this type of procedure to make sure that the hospital gave us all the records so that the people going in to the hospital don't see any records other than what may have been considered by the medical records librarian as a cancer medical patient.

MR. WEISS: Unless that cancer patient happened to have other diseases, we wouldn't see the record at all.

MR. GELLER: We have had no requests for this, but the question has come up about case studies, in other words, where, as an example of a while back, there was a piece in the newspaper about the vagina in young females where the mother was given Sebatrol during pregnancy some 20 years ago, and could we identify cases of people who want to do more detailed studies about this?

The decision at that time was that we would identify hospitals where these patients would have been hospitalized or treated, but we would not provide any other information.

They would have to go back to the hospital and work with the hospital board and the doctors in the hospital
to get the cases.

MR. SCHNEIDERMAN: In other words, get the local permission, just as if they were doing a local study in the same manner, as they would normally have to go about doing it within that institution.

MR. GELLER: This is another indication of usefulness. We can identify these things quite rapidly and get a large number of cases. At this point, back in 1969 when these cases were not coming to diagnoses, we had very few.

But in 1970-1971, I assume we will have a larger number of cancer of the vagina.

MR. SCHNEIDERMAN: It is just beginning to appear now in this country.

MS. GROMMERS: Thank you.

MS. NOREEN.

MS. NOREEN: Yes. I was wondering if you saved the files you collected on individuals from past surveys.

MR. SCHNEIDERMAN: No. These have been destroyed.

MR. GELLER: In fact, this is one of the problems. We are trying to resurrect the 1947 data. We can do more detail between the past and between the present data. We haven't been able to at this time.

MR. SCHNEIDERMAN: We haven't been able to. They have been destroyed and we are planning to destroy these, too.
MR. WEISS: I might add that in effect, each process cycle we go through, we incinerate an enormous amount of material. Nothing is placed in the wastepaper baskets.

MS. GROMMERS: With proper air pollution control.

(Laughter)

MR. SCHNEIDERMAN: I never realized it, but my military experience fitted me for this. I was at one time a confidential garbage man at Wright Field. I was the lowest Wright Second Lieutenant at Wright Field at the time, and my job was to see that all secret and confidential documents were incinerated, and here I am back some 25 years later doing the same kind of thing.

MS. GROMMERS: One never knows when one's training will come in handy.

MR. SCHNEIDERMAN: Yes.

MS. GROMMERS: Professor Weizenbaum.

MR. WEIZENBAUM: Yes. Just a small question here, not with respect to medical stuff, but other information.

In Congress, Senator Irving, for example, gets guarantees from several government officials -- that he won't name -- that certain files have been destroyed and there is no way, generally speaking, to demonstrate that they have been destroyed, the identification of that.

Do you know or have you thought about any procedure
that would in fact satisfy people that files have been destroyed?

For example, do you have a system set up of statements of witnesses who have seen it actually go into the shredder or things of that kind?

MR. SCHNEIDERMAN: We haven't done it so far.

MR. WEISS: No. We have not taken the active role here in attempting to do that. The procedures that we have set up are documented and are available for review.

But we have not taken up a fairly passive role, I agree; we have not taken an active role to demonstrate to the public or the Congress.

MR. WEIZENBAUM: You don't give a tape reel to a young man and say, "Destroy this," and the fact that you do not see it again satisfies you that it is destroyed? You do have some control over that?

MR. WEISS: What we have done is we have a pool of magnetic tapes which are totally dedicated to the survey so that a tape doesn't wind up in someone else's hands, usually.

There are some interim work tapes at computer centers which we don't have that kind of control over. But we have a fixed pool of tapes that we use at our computer center and fixed pool at our data converters and these tapes are always stored in locked cabinets and we don't allow those tapes to be used outside.
If a tape becomes in poor condition, we degauss the tape. We erase that. We definitely take *steps* to do that and insure that it is done.

MS. GROMMERS: Mr. De Weese.

MR. DE WEESE: I wanted to ask if you follow these people through a period of time, months or a year. After you get the medical records, do you follow their cases or is it just an *incidence* report?

MR. GELLER: The cases are not in a sample. If they come back to the hospitals, the medical facilities, we will get initial reports on that. Obviously, when the patient comes in, the record will be given to the administrator.

We don't look for these. On the samples, since we are interested in getting everything, they have the care given to the patient and the cost of the hospitalization, and we actively ask the hospital "Has this patient been in the hospital back some time," and "May we have the records even though the case may not appear as a cancer related hospitalization?"

We want the people to look through the case to make sure that no cancer treatment was given at that time. So we do follow the 10 percent sample for all the hospitalizations for a two-year period after their first diagnosis.

MR. DE WEESE: So if he would come in for psy-
chiatric care, you would get that information through that process?

MR. GELLER: Yes.

MR. DE WEESE: The other thing I want to ask you is what type of people serve on your committee? How did you select these people and what disciplines do they represent?

MR. GELLER: We have two committees: one, epidemiology committee; this is made up of epidemiologists and statisticians from the government, American Cancer Society and universities.

The medical care, medical economics, which again are made up of health economists, people, plain economists and statisticians, either universities, through Blue Cross, medical organizations like HIP in New York.

MR. DE WEESE: Would you think it might be a good idea to possibly have a civil libertarian type person represented on the committee in some confidential matters as opposed to a scientist?

MR. SCHNEIDERMAN: I think so, yes. I talked to John Silard here in town. He is the civil rights lawyer of Rauh and Silard. They are one of the very active civil rights people.

I talked with John Silard about this from time to time. He is a friend and neighbor, and I trapped him into being on a couple of programs -- one program, the
American Statistics & the Problems of the Ethnics of Human Experimentation, and I haven't succeeded in trapping him into another one of our committees yet, but I will try.

MS. GROMMERS: Mrs. Hardaway.

MS. HARDAWAY: Yes. I would like to take a minute just to thank you for your work and wish you much success in it because you gentlemen have made great impact upon our personal lives and I am very impressed with you gentlemen and I wish you the very best success in what you are doing.

I glanced through the folder but I did notice on each form that you had the social security number. May I ask why have you included that number on your form?

MR. GELLER: This is one way of identifying patients, but more importantly, we had, early in the survey, investigated the possibility of working with social workers and Medicare to get sort of an exchange of information between Medicare and the survey.

They would provide us with the information and the cost to that patient and we would provide them with some diagnosis information which they don't have. They don't code all their diseases.

Since we are coding all the cancer, we can provide them with a code which will save them a lot of time and energy. We are still working on it. We are still not success
That was the main purpose, though.

MS. HARDAWAY: Let me ask you your personal opinions. We have had some discussion here in the last two days concerning what is public information and what is not.

Would you have any feeling that, if I were, for instance, a welfare patient and depended upon that for my source of income and that I had cancer and became a part of your record, that because I was in the condition of depending on the government for my livelihood that that in any way would make my record -- that you would have control over -- any sort of public information that would carry my name?
MR. SCHNEIDERMAN: Not any more than if you were a
patient at the Harkness Pavilion at Columbia University -- you
know, the big University Pavilion where, to the surgeons and
nurses, a patient is a patient no matter what he gets paid
for, and in view of what may be changes in the medical econom­
ics in this country over the next ten years, it may very well
be that everybody gets his care paid for in a similar way,
quite apart from his source of income. So I don't think --
so as far as I'm concerned, it doesn't make one bit of differ­
ence.

MS. HARDAWAY: Thank you.

MS. GROMMERS: Professor Allen.

MR. ALLEN: On those things that are within your
control, it is obvious that somebody has been quite meticu­
lous in being very careful. But are there some aspects around
the Boarder that you don't have complete control over that have
created any problems? Have you had any subpoenas issued on
record or other aspects that perhaps might be helpful that
are not directly within your control that might create prob­
lems with respect to confidentiality?

MR. SCHNEIDERMAN: We have had no subpoenas issued
on us so far as I know for records. The major thing that is
really not under our control are the records at the field
offices because they originally belonged to the hospital. The
records belong to the hospital, belong to the patient.
I think the lawyers are going to be struggling with this for some time as to whose record is this, who does it belong to, who has a right to sort of let it loose. I anticipate that there will be struggles in relation to that. At least, John Silard tells me there is going to be troubles on that. He is of the mind that the records do not belong to the hospital or the physician. They belong to the patient, and this is an interesting concept which I think might cause some real rows.

MR. ALLEN: Would it any way impede your effort if those records, as they came from the hospital, the names were separated from the data and in separate files so that they could belong back to -- so that the same person wasn't accounting for both the information and address?

MR. SCHNEIDERMAN: On the first abstracting of the data which is generally done at the hospital, it is physically done at the hospital, the first abstracting of the data, this separation does occur because when you are picking up the hospital record, you cannot know that there is not a name of a patient on it, but from there on in, they are separate.

MR. ALLEN: That is the point which you are urging the persons that you have control over to not be mentioning any names?

MR. SCHNEIDERMAN: Yes. Yes. You've reminded me, the first job I had was an office boy in a large corporation
and one of my first jobs, I was told, "nobody in the corporation is supposed to know what the other earns," and one of the first jobs I was told to do was to go file the W-2 forms but not look at the names of the people and how much they were earning. You know what that did to me. So it is hard sometimes to resist the temptation.

Ms. Grommers: Ms. Lanphere.

Ms. Lanphere: Well, sir, my points have already been answered. I just have one quick question.

The cancers that are just treated in the physician's office, then, of course, they are not hospitalized, and you don't receive any --

Mr. Schneiderman: We do receive information. Would you please speak to that.

Ms. Lanphere: From office visits?

Mr. Geller: Early in the survey, there was a mailing sent out to every physician in the area asking him to report any patient he treats for cancer and indicate whether the patient has been hospitalized or has to be hospitalized. If there is indication the patient has not been hospitalized, we send him out doctor report record and ask him to fill it out and send it back to us.

There also was another sort of substudy of the major study and this is on skin cancer which is a problem, collecting data statistics on skin.
MS. LANPHERE: I was wondering how you got the number of skin studies.

MR. GELLER: For a six-month period, we had a special skin survey. Most of the records came from private physicians. We had most of the forms assigned to the areas sent out. This again was in four of the areas, not in all ten areas. We did get reports from the physicians. They have been very cooperative in this.

MR. SCHNEIDERMANN: Our estimate was that the total number that the average physician would have to make in the course of a year would have to be ten or fewer, and in our field test in Birmingham, we discovered among other things that our physician report form was too extensive. So we did change it to make things easier for physicians.

In those particular instances where a physician has specialties which will bring him a lot of cases, we will send someone in to his office to help him prepare the record, or with his secretary or his receptionist so as to make the burden on the physician as small as possible.

MS. LANPHERE: But the patient for that dermatologist or whatever would not know?

MR. GELLER: That's right.

MR. SCHNEIDERMANN: That is correct. That is right, unless, of course, he indicated to his people that he was providing this information. Some physicians do do this.
MS. GROMMERS: Mr. Impara.

MR. IMPARA: Just a question to satisfy my own curiosity in terms of your survey technique. Did you reimburse any of the respondents, either the hospital personnel or physicians' personnel for participating in this sample?

MR. SCHNEIDERMAN: No. There is one -- to break in here -- in the Detroit area, they are now going to extend on their own the kind of thing that we have done. It is being operated by one of the sharpest guys that I know. He is now charging the hospitals to include their records in his system. He turned the thing the other way around and it looks as though he is going to make it.

MR. GELLER: He provides a great deal of service.

MR. SCHNEIDERMAN: Provides a great deal of service, but he is charging them so that their patients will be included in the records.

MR. IMPARA: Professionals will pick it up one way or another.

MR. SCHNEIDERMAN: Yes. Unfortunately.

MS. GROMMERS: Mr. Anglero.

MR. ANGLERO: As you know, I am from that small island that is so much different from the rest of the United States.

(Laughter)

MR. ANGLERO: And the help is not only because of
the cancer situation. There are some other things that make it different, even with the weather.

Well, you mentioned in Puerto Rico you didn't go through specific histories. You went through the cancer registry.

MR. SCHNEIDERMAN: Yes. We worked through the cancer registry.

MR. ANGLERO: So the sample wasn't taken there, as such?

MR. GELLER: No. We are not doing the special study in Puerto Rico.

MR. ANGLERO: You work with the cancer registry?

MR. GELLER: With the cancer registry.

MR. ANGLERO: Do you get all the information you need from the cancer registry.

MR. GELLER: Yes. They have been developing the cancer registry for quite a long time. It has been over ten years that I have been working with the people in Puerto Rico, before I came to the Cancer Institute, and they have as good a rapport as most cancer registries in this country and we felt the data was fairly complete.

MR. ANGLERO: It is not because they work in some way for you? It is not because of that?

MR. GELLER: No. This was even separated from our going to go to Puerto Rico. The only reason for going to
Puerto Rico, we felt the cancer registry reporting was fairly complete and there would be no problems.

MR. ANGLERO: All right. I will put off that one question later and ask that. There was one other thing. You went through the dead people's files?

MR. GELLER: The death certificates.

MR. ANGLERO: Also in Puerto Rico?

MR. GELLER: Also in Puerto Rico.

MR. ANGLERO: Was there any kind of consultation or permission of parents of these deceased individuals?

MR. GELLER: No.

MR. ANGLERO: Nothing like that. How did you manage? Just take it from the --

MR. GELLER: Well, the cancer registry is with the Commonwealth Health Department, and the Commonwealth gets a copy of the death certificate.

MR. ANGLERO: In other places besides Puerto Rico?

MR. SCHNEIDERMAN: The same sort of arrangement.

MR. GELLER: The data is with the local office of statistics. They provide either a copy of the death certificate or the microfilm file, and they went through and abstracted the data of the cancer deaths.

MR. ANGLERO: No consultation was given, to consult the relatives?

MR. GELLER: No.
MR. ANGLERO: Did you provide, in this particular case, the consultation of tabulations with all the information that you get from them, do you plan to do it in all cases?

MR. SCHNEIDERMAN: Yes.

MR. GELLER: Yes. Yes.

MR. ANGLERO: And in all cases, also?

MR. SCHNEIDERMAN: Yes. The registry will have the complete tabulation that we have.

MR. ANGLERO: I put down the question different. Suppose I have looked at this for a while, at this format, and suppose it is not permissible to get a personal data, identifiable data, name, address and all these things from any individual to make a study like this, how would you proceed? How would this affect your study?

MR. SCHNEIDERMAN: Let me comment on this. There are two reasons for getting out identifying information. One is so that we shall report each individual only once.

If a person goes to a physician, the physician reports him and he goes to the hospital and the hospital reports him and then he goes to another hospital and that hospital reports him, then the pathologist reports him, well, we'd like to call this one. We don't want to call it four cases, but one.

Certain information enables you to tie the report to a specific individual, and so for that reason, we need some
kind of identification.

In prior surveys, we actually used some of the name-scrambling techniques. What are they? The vocal type, rewriting of the name. What are they? Sound --

MR. WEIZENBAUM: Soundex.

MR. SCHNEIDERMAN: Soundex, to scramble this. But nonetheless, to enable us to make these matches as necessary.

The other part for the information obviously was where we wished to get more detailed information, so we needed the identification of the individual so that we could go back to him if we got the permission to go back to him, so these are our two major reasons for requiring identification.

MR. ANGLERO: I am not a specialist on this. I know that Professor Weizenbaum is better, but suppose if I deal with a hospital in a country like this, it's just to get information of some kind of linkage number but not more than that, would it be possible for you to carry on?

MR. SCHNEIDERMAN: It is not impossible, no.

MR. ANGLERO: So I would say at this moment that probably you wouldn't need to have in your center files, this information, this data?

MR. SCHNEIDERMAN: If this is a universal-type number in the sense that if the individual appears some place else at another hospital which has a different numbering sys-

25 tem, we could tie it to the number in the first hospital.
Hence, a number like the social security number, you see, would be such an identifying number and you could avoid using a person's name if you had the social security number.

There is obviously the technical difficulty in using social security numbers in that people write down the numbers wrong, you know. They invert digits and things of that sort and then you are never sure if you have the same person.

But if we have the same number with an inversion, then it is very likely to be the same person. Somebody has just written it down wrong.

I would be happy if the social security people who started it knew something about error-correcting codes and adding another digit with an error-correcting code so we would know whether the numbers had been inverted. Some of Ms. Cox's students have done work on this. It is a very nice device. It has a number and a tail on the end of the number to tell you if those numbers, as written, are right, but those do not exist.

MS. GROMMERS: Mr. Siemiller.

MR. SIEMILLER: I am really well pleased this morning with the report of the sensitivity for personal privacy that is being carried on in this particular report or program and rather alarmed at your disclosure of what is happening in Detroit. I hope they don't spread, because if it did, every employer would be charging his employees for the opportunity
to work in his factory or work place, and I just don't want that to happen.

(Laughter)

MR. SIEMILLER: That's all I have.

MR. SCHNEIDERMAN: Don't tell anybody.

MR. SIEMILLER: I won't.

MS. GROMMERS: Mr. Davey, did you have a follow-up question?

MR. DAVEY: Could you tell us a little bit about the unit cost involved with this particular system? How much does it cost per record or whatever it is on a unit basis? Do you have any feelings about this at all?

MR. SCHNEIDERMAN: We have. Mr. Weiss has put together our total computer cost in this over, essentially, the fiscal years 1968 through 1973, through which we will work, and we estimate it will cost us $7 per case by the time we have completed all the things, including all our tabulations, all our runs, all our publications of this sort.

MS. COX: Of the descriptive type?

MR. SCHNEIDERMAN: Of the descriptive type, not including the analytical cost of the epidemiologist and so forth.

MS. HARDAWAY: May I ask just one question. Obviously, you are a good administrator.

MR. SCHNEIDERMAN: Well, thank you.
MS. HARDAWAY: How much, how many decisions that are made are simply because you are a good administrator, and how many of them are because they are a written policy? In other words, if you should leave your position tomorrow and a new administrator would come in, that would not be as qualified --

MR. SCHNEIDERMAN: Well, frankly, none of the decisions are made because I am a good administrator. It is because I have a superb staff and these people have set up the whole thing and they have written the detailed manual and they meet regularly on problems.

We have some nasty nit-pickers on our staff. We write instructions and you come to the next meeting and, there, Sue sits. Sue is one of them. She's real sharp. She says, "Here are all these cases that don't fit these descriptions. Let's get an answer to this." You try to shut her up and she won't shut up.

Eventually, by and large, what we have come up with is a great number of people contributing to it, people who have contributed a great deal.

Dr. John Christian Bailar III who started this thing is no longer with the Cancer Institute but is now one of the directors of the VA and is responsible for most of what you have heard here today, and if you want to commend somebody, commend him, please.
MR. SIEMILLER: I'd like to observe on that, that one good man at the top can make all the difference between success or failure in any particular program whether it is a business, whether it is a trade union or whatever it is. The one individual that cannot pass the buck, his decisions are most important and it can be the difference between success and failure.

MS. GROMMERS: Can I follow up a little on that from what Ms. Hardaway commented on. What it also means is that if you and your staff left, that there would be no guarantee that the next staff would be able to or would be required to continue this?

MR. SCHNEIDERMANN: Well, I think if we all left, en masse, yes, then we'd be in trouble.

MS. GROMMERS: Is there any way that that could be prevented?

MR SCHNEIDERMANN: Raise the federal pay, taxing.

MS. GROMMERS: Is there any way --

MR. SCHNEIDERMANN: Excuse me for that facetious answer.

MS. GROMMERS: No. All right. Is there any way that it could be prevented in light of our inability to raise the federal pay and that your staff and yourself would leave, but nevertheless the requirement for continuing your practices and policies would be met?
MR. SCHNEIDERMAN: I think it would be possible with the director of the Cancer Institute, but in fact I know in terms of the previous director and the current director, these men are both committed to doing this and to continuing to its completion.

MS. GROMMERS: Is there any law that --

MR. SCHNEIDERMAN: No. This is not required by law.

MS. GROMMERS: This is Ms. Hardaway's comment, not me. I was pursuing it here. Is there any way there could be a law in a different way? Are you aware of where the authority for such a law would lie?
MR. SCHNEIDERMAN: At the moment, the law is permissive rather than obligatory. What exists within the law permits us to do this kind of thing but does not require us to and, in fact, in a sense, I am rather pleased that it doesn't require us to, because this is the last time we are going to do a nation-wide survey of this type.

The reason this is the last time we are going to do it is we think we are in the process of discovering some better way of doing this and getting the stuff more current.

MS. GROMMERS: I am sorry. I haven't been exactly exclusive here. Were are talking about not your survey, but the method in which you conducted your survey in assuring privacy, and I know of the incidence question and that is why I am pressing you for it.

Section 305A of Public Health Service Act authorizes the Secretary to conduct the National Health Surveys and Studies, and it considers the following -- et cetera.

MR. SCHNEIDERMAN: In that sense, then quite obviously people who follow us would have to follow the legal limitation.

MS. GROMMERS: I will read this:

"No information obtained in accordance with this paragraph may be used for any purpose other than the statistical purposes for which it was supplied except pursuant to regula-
tions of the Secretary; nor may any such information be
published if the particular establishment or person supplying
it is identifiable except with the consent of such establish-
ment or person."

These are then regulations of the Secretary?

MR. SCHNEIDERMAN: No. These were not in this
particular operating manual. We constructed or put together,
in terms of restraints placed on us by the law and regula-
tions, this manual so that in a sense, I suppose you could
consider it the instructions of the Secretary.

We are acting as his agent.

MS. GROMMERS: And you are really interpreting
his regulations?

MR. SCHNEIDERMAN: Yes.

MS. GROMMERS: And someone else would reinterpret
his regulations?

MR. GELLER: We have one restraining in that the
whole survey, the forms in the operation was approved by
the Office of Management and Budgeting, and there is a sup-
porting statement in the manual which we had supplied to the
Office of Management and Budgeting, detailing how you can
conduct the survey, what steps you are going to take to
maintain confidentiality.

MS. GROMMERS: Including this?

MR. GELLER: No. That manual wasn't in existence
at the time.

But there is part of the manual with a section of our supporting office to the Office of Budget OMB, as it was at that time.

MS. GROMMERS: Do you see any impediment in your working office if this were to be required by law, to the way that future studies were carried out?

MR. WEISS: I would like to answer that question in one way. The forms are required to be submitted to the Bureau of the Budget -- or in those days, it was the Bureau of the Budget -- before we could actually use them, as well as a description of our whole approach to the survey and the conditions and restraints under which we intended to operate.

This was submitted to OMB and there was a great deal of discussion at the time.

I think that depending on OMB's controls and the extensiveness of their review, that does impose, to a certain degree, a great deal of control over us as to what we do.

If we had to develop essentially the procedural manner and a system in order to present that to a review board before we could proceed, we would be spending incredibly large amounts of money, possibly without assurance that such a study would be conducted.

I think we went as far as we could for approval.
before we began the major operations of the survey.

MR. SCHNEIDERMAN: Let me address myself directly to you in support of Mr. Weiss' remarks and address myself directly to your last question.

I think I look upon myself -- I don't know whether I really am or not -- my image of myself is I am a libertarian, a civil libertarian; and as well as a civil libertarian, a research libertarian in the sense that I won't want to impose rigidities on the research community, myself, or anybody else that may tomorrow prove to be limiting or handicapping.

That does not mean that I don't want to work within the limits imposed on me by law and by good decent behavior with respect to other human beings. I think we have achieved that in this study.

We have tried very hard to respect confidentiality respect privacy.

I would not like to see a manual which is sort of a set of operating procedures really become involved as part of a law, become that rigid. I think this thing that we have here is a good set of operating procedures.

I think people who follow us can probably make a better set, and, nonetheless, consistent with the rights of the individuals from whom we are collecting data.

I would hope that they would make a better set
respecting the rights even more than we have.

That is where I think I would be reluctant to indicate I would want to include it as part of the rigid operating procedure.

MS. GROMMERS: There may be some part, though -- I just want to finish that one sentence now.

MR. SCHNEIDERMAN: Yes.

MS. GROMMERS: There may be some point, though, if you were thinking about this when you looked through this and said, "Now, these things we have developed are pretty clear. We want them but there are some other things that will be premature to close on them. There are other things that might have research limitations involved to develop a process for, partly solidifying what turned out to be good, and practical in keeping with the rest" --

MR. SCHNEIDERMAN: Yes, yes. This certainly makes great sense to me.

MS. GROMMERS: Mr. De Weese.

MR. DE WEESE: I think what we are talking about is more general outlines, outlines of guidelines, for example, keeping the name file separate from the other files.

Would you support this as a statutory provision applicable to all similar research types?

I mean, this is the type of general -- or the idea of having a committee to advise you on privacy issues,
these are the types of general --

MR. SCHNEIDERMAN: I see what you are driving at. I sort of got the feeling you were looking at some of the detailed technical things rather than the principal.

MS. GROMMERS: Yes. Yes, I was. This is in addition to it. This is another kind of question apropos same problem.

MR. SCHNEIDERMAN: Certainly I will accept the things you have remarked as to certain studies, in basic humans.

MR. DE WEESE: You would support that in statutory terms?

MR. SCHNEIDERMAN: I think I would, yes.

MS. GROMMERS: I was pushing it one limit over here to see whether you could take it.

MR. SCHNEIDERMAN: And I was resisting.

MS. GROMMERS: Mr. Gentile.

MR. GENTILE: I would just like to point out, whereas there are certain statutory requirements in this field, that there is an immense area that could be covered through administrative procedures..

I think these gentlemen have demonstrated that, and I fear that too often, too many of us try to legislate privacy or legislate something into being, and it doesn't work that way.
We just heard yesterday from one of the drafters for the Freedom of Information Act that here is a bill -- or a statute that has been on the books for five or six years, and he doesn't really feel it has been adequately implemented.

So I think that we have to come up with some of the very positive measures and guidelines, some samples such as in that book that was presented to us today and then have the administrator implement it, develop it for his own area and hold him accountable.

I think there is no substitute for that.

I would like to make a sort of parenthetical remark. In the sense that we have been fortunate that American physicians are suspicious of the Federal Government, they have given us a hard time all along the line in any of these things that we have wanted to do, and although we have sometimes resented them and said, "Oh, we wish you'd go away and leave us alone," I think the net result is that we have to come up -- I hope we have come up with a really decent way of going about collecting these data and protecting the privacy of patients and protecting their rights as individuals and human beings.

As I say, some of it looked to us like real reluctance and foot dragging, but it is not all bad. In fact, it has been very good.
MS. GROMMERS: Mrs. Cox.

MS. COX: Just one question. Going back to the pressure a little bit, what would happen if you were not heading this? You still have all the -- overall, the collecting agencies, national statistics centers here.

MR. SCHNEIDERMAN: Yes.

MS. COX: The Office of Management and Budget.

MR. SCHNEIDERMAN: Yes.

MS. COX: Now, we hate it sometimes but it still is -- and is becoming more so, I think you will agree -- a place where these things, these laws and these things are checked on and they are always trying to have smaller schedules and smaller schedules.

I mean, there is a lot of that in the direction coming in and we will have Shiskin here this afternoon.

ME. WEISS: That is quite true. We went through a lengthy process period.

MS. COX: It is a long ordeal.

MR. SCHNEIDERMAN: We have been fortunate that the communications are quite open between us and they are free to talk to us informally and we have been free to talk to them informally, and that helps, too.

That means we come to a meeting of the minds quite quickly.

MS. COX: And that is the Office we want to be sure
it is kept in -- of course, all week, like this, too, this committee.

MS. GROMMERS: Mr. Anglero.

MR. ANGLERO: I want to say that according to the manual there is what is called the state plan. By HEW, and I think the other agencies also do it, and so as an agreement between the federal government and the agencies and the local and state agencies, these are binding as to how these agencies will operate.

They cannot be changed easily even though there is a change of administration, local or state agency or either the federal government.

I think that some kind of formal -- formality could be given to the documents like this when they are presented.

MS. GROMMERS: If you add to that Mr. Gentile's suggestion of periodic review, you could possibly separate things where it turned out that there were always some good practices to do and other practices where you may have problems and develop some problems.

Mr. Martin had a question for you.

MR. MARTIN: Could you indicate what result you anticipate might flow from the conduct of the first two and third national cancer survey?

MR. SCHNEIDERMANN: There are three things that we
are trying to get out of this. We are trying to get a base
in terms of the total impact of this disease, total number
of patients, what kind of disease and, roughly, where it
exists so that the medical planners may be able to do their
planning for medical facilities.

MR. MARTIN: I understand why you are making the
survey. But I would like to know, as a result of having the
first two surveys made and then the third one going on, what
is the total cost of the third?

MR. SCHNEIDERMAN: The total cost, including all
of our staff, will be about $7 million.

MR. MARTIN: So, okay. Perhaps you have know-
ledge of what has happened as a consequence of the first two.

What in fact did happen? I realize why the
surveys were conducted. The intention is clear, but in fact,
what happens?

MS. GROMMERS: Cost effectiveness.

MR. SCHNEIDERMAN: I think the first service came
to impetus in the epidemiology of lung cancer which then led
to smoking as a factor.

Now, out of this survey all by itself, you know
how science works, people contribute here, a little bit here,
a little bit there.

Somebody gets an insight and pulls it all to-
gether. The survey gets an important part in the contribution
to that.

I think some of the awareness leading to further research in the treatment of various forms of disease have come from the survey -- again, not from the survey purely alone, but from all the awarenesses and then pulled together.

I think, for example, that in the treatment of breast cancer in this country, we are going to move farther and farther away from the radical mastectomy, full removal of the breast kind of thing, in part, because some of the information which is being developed here would lead to other people developing information which in turn leads the surgeons to, perhaps, back away and look more closely at their data in terms of, "What do we get besides this radical surgery?" less radical surgery?

In Europe, they are doing lump breast surgeries. I think they are going to bring women in much earlier so they will be treatable. So these are some of the things that are coming in.

MR. MARTIN: Can you cite any evidence on the basis of which of these consequences could have been said to have resulted?

MR. SCHNEIDERMAN: Oh, you have really got me back against the wall. You know, I would really have to work on this. I couldn't, off the top of my head.

MR. MARTIN: It isn't part of survey processes or
institutes of NIH generally to try to determine what the consequence is?

MR. SCHNEIDERMAN: No. It has not been. You know, the Cancer Institute has now been, just in the last legislation, been given not the authority -- what shall I say? -- orders by the Congress to get involved in the cancer control activities.

In order to do this, in a meaningful way, the survey data will be extremely important. Should we really spend, as some people have suggested, $10 million for improving treatment care facilities for those additional thousand said children with acute lymphocytic leukemia? Shall we spend it on the other question?

MS. GROMMERS: Terrible. That's terrible.

MR. SCHNEIDERMAN: A dreadful question that cannot be answered. If I was the parent of a child with acute lymphocytic leukemia, it is apparent what I would want. But these are the kinds of things we are going to have to look at very much from the cost point of view.

MS. GROMMERS: I have to challenge that. Why do you have to look at it from that way? This is not Mr. Martin's question. This is just in answer to your last statement, and I can't let it go by like that.

MR. SCHNEIDERMAN: What alternatives would you propose to me in terms of spending the money our Congress says
we have to spend?

MS. GROMMERS: Measure how many horses go by and say that the increase in the number of horses is going to allow you to decide how many children should be treated and how many facilities should be built.

MR. MARTIN: Or any other completely unrelated piece of data.

MR. SCHNEIDERMAN: What you are saying, I guess, is a life is a life and we ought to do what we can to protect it under all the circumstances.

MS. GROMMERS: No. I am saying that the cost of treating something isn't reliable or a reasonable measure of whether it should be done; that is, the observable cost of dollars.

MR. SCHNEIDERMAN: I think we have to talk at coffee break.

MS. GROMMERS: That's okay.

Would you like to ask some more questions?

MR. MARTIN: You have obviously, and I think to everybody's delight, given a great deal of thought and attention to problems of confidentiality and so on.

As this was done, with reference to what hazards were you operating such care, the statutory obligation to minimally respect the section -- the relevant section of the act? What incentives, for example, do you think exist
for one to obtain information and use it for some purpose that you would regard as improper against which you strive to protect, from these insidious methods, care?

MR. SCHNEIDERMAN: Well, I personally am concerned with my own personal privacy and I guess I extend this to other people. I think they are concerned with their privacy as I am for mine.

I try to give an example where we felt it would have been improper to have given the specific individual information where someone wanted to go out and find out -- for example, the lawyer wanted to find out how the other women had been treated with this disease. I feel this was certainly an invasion.

MR. MARTIN: But as you plan, you have a sense of what the risks are that one is seeking to guard against by these careful methods.

There is a lot of talk about --

MR. SCHNEIDERMAN: Yes, yes.

MR. MARTIN: -- the possible disadvantages that would flow from information coming in to wrong hands, being used for purposes that it isn't intended for.

I just wonder whether the group has given very careful attention to designing a secure system, or has in the first instance, some idea of where the group was designing this in terms of some sense of the risk they are trying to guard against.
MR. SCHNEIDERMAN: I think when you were talking about medical research, a patient care over a long period of time, you begin to get the feedback from both the patients and the physicians who are treating them, of the kinds of patients, the patients ought not to -- patients or their families ought not to have to suffer in addition to their illness. I have been involved before with -- we have been working on this and I have been involved in a large-scale experimentation in treatment of cancer through the chemotherapeutic agents and I found very often in our discussions there where we got involved at "Shall we do this? Shall we not do this? How can we do it?" -- with a concern of what it meant to the patient, not as an ill patient, but the patient as a person. And I think this kind of respect for human beings as persons really underlines a great deal of what we were doing here. I think we would have done most of this, or I hope we would have done most of this without even these statutory requirements and limitations.

MS. GROMMERS: I think what Mr. Martin was getting at, very specifically, is what do you think might happen if you lost your privacy?

MR. SCHNEIDERMAN: I don't want my neighbor talking about me. It is as simple as that -- unless he says nice things.

MS. GROMMERS: Are there any other questions? We
just have time for two more. Senor Anglero.

MR. ANGLERO: I would say along with Mr. Martin's question, what is happening if, instead of dealing with medical records, you were dealing with other kinds of records; would you put the same kind of confidentiality to that?

MR. SCHNEIDERMAN: Yes, I think I would. There are records that militate against making known some specific aspects, sometimes militate against the best interests or the welfare of that individual. Ms. Cox, I recall, and I had a talk about the problem of making information known for even certain groups with respect to IQ scores and what the people do with these and what can be done with them and what happens to people who are members of this subgroup when the information is widely publicized and perhaps used by people who don't know what it means. It could be used for less than the most honorable purposes.

MR. SIEMILLER: Derogatory. We used to have a vice president that wouldn't say that. He used to say "derogatory."

MR. SCHNEIDERMAN: That's treating people like dogs.

MS. GROMMERS: Mr. De Wesse.

MR. DE WESSE: Sometimes, I think we forget that the data is completely devoid of any personal identification. It's just facts and figures and can also have a very compro-
missing effect on individual rights, and I point to this
document you just passed out today. In your presentation,
you made a specific point that one of the principals or
variables in the incidence of cancer are social and economic
status, but in this entire report, there is no mention of
social status.

Every graph, every table, every chart is based on
race. I guess the distinct impression from reading this, as
a layman with no expert knowledge, I would conclude that Blacks
are susceptible to cancers.

MS. GROMMERS: Yes. That's the impression I get.

MR. SCHNEIDERMAN: You know, we look like our par-
ents and we are bound by our intellectual parents. What
people do to data when they get it in this country, data con-
cerning illness, they do it by age, race and sex. We do it
by age, race and sex, so we have data comparable so that we
can put it together. When we have data comparable to age,
race and sex, we ask ourselves, "What does this imply? What
does it mean?"

We then have to go and ask, is it the race that
has -- that leads to a greater incidence of cancer of the
uterine cervix, or is it socio-economic conditions? And you
look at this in detail and you find you are able to break it
out and then you can do something in prevention of the disease.

Now, we will have socio-economic information, by
the way, in some of the later reports. But I, for one, at this
time, it is my personal opinion there -- some of my colleagues
don't agree with me -- I look upon race in this country at
this time as an easily identifiable marker for socio-economic
conditions.

MR. DE WEESE: Isn't that dangerous practice?
Doesn't that foster a certain amount of alienation?

MR. SCHNEIDERMAN: I think it is less dangerous
than taking the other point of view that this is a kind of
immutable thing of which I know nothing.

MR. DE WEESE: I'm sorry. I don't understand.

MR. SCHNEIDERMAN: Well, if I can find that the
race is a marker for socio-economic conditions and I can do
something about the socio-economic conditions, then I can de-
crease the incidence of the disease and I could do something
useful.

If I say the disease cures because of race, this
is something I cannot do anything about. And that, to me, is
a dangerous thing for me to say.

You are asking me to throw up my hands and say I
can't do anything about it. You just report it and there it
is.

MS. GROMMERS: What are the possible markers that
you could have used? That was one. Presumably, what you are
saying is you used it because everybody else has been using
MR. SCHNEIDERMAN: I used it because we want to compute rates and we want to compute incidence rates, and that is how you can do it.

MS. GROMMERS: Because everyone else has been using it, too, you are just perpetuating --

MR. SCHNEIDERMAN: That's right.

MR. DE WEESE: But you see, sir, I have to make the conclusion --

MR. SCHNEIDERMAN: But if I didn't break it down in terms of the way the data report is, the way other people report their data, if I didn't report the data by age, sex and race, I couldn't do something useful.

MS. GROMMERS: Somebody's got to begin.

MR. SCHNEIDERMAN: It's useless. Useless. Lots of people are useless.

MS. GROMMERS: No. Somebody's got to do it in a useful way.

MR. SCHNEIDERMAN: I think we are all looking at it in useful ways.

MS. GROMMERS: We have one more question.

MS. KLEMAN: You mentioned on trying to work towards matching your records with social security records. Are you planning to or are you in the process of trying to match with any other kinds of records, for example, Medicare,
Occupational Section files, Census files?

MR. GELLER: Well, one of the things that Marvin eluded to is that eventually for the full data, we will try to divide a case by socio-economic class using census -- small area census data or other socio-economic data where we can find our data and census data. We are intending to do that.

MS. KLEMAN: What about the records, individual by individual, the way you do it, the Medicare files by using the social security number?

MR. WEISS: We have been exploring that since the beginning of the survey, as a matter of fact, about the possibility of doing that. If it were done, the Census Bureau has very strict regulations as to how that is done. They would never provide us with any information files, individual by individual basis. All we could get from the Census Bureau are tabulations.

MR. SCHNEIDERMAN: At this point, it doesn't look like the prospects of matching is very good. We are doing things from NIOSH.

If we are looking at geographic cluttering or age cluttering as clued to where NIOSH ought to go in where the industrial relations people are involved, in that area and that section, that area might be it. In fact, we had a meeting last Friday on this specific problem.
MR. GELLER: I want to answer your question. We did investigate the record, the linkage between their record and our records. Some things we would want to look at is on a sample basis. Ours is a ten percent sample. Theirs is a 25 percent sample. This match would be small.

The other problem is the cost of record linkage which is very important. We just couldn't afford it.

MS. KLEMAN: How much? How much?

MR. GELLER: I don't know. Something like $10 or $15 a record.

MS. GROMMERS: That's not what they charge to you, is it?

MR. GELLER: To our files against their files, to see if we have a match on this case.

MS. GROMMERS: Their charge to you?

MR. GELLER: Oh, definitely. Everything is charged.

MS. COX: It is very expensive.

MS. GROMMERS: I would like to ask one final question and we'll have a coffee break. Now, suppose you did change your system, suppose you did go on this plan and you did everything that might prevent -- and since the social security number would be on those files -- prevent unauthorized accidental leakage of this information to the Bureau of Vehicles, for example, through a computer terminal, what would --
MR. SCHNEIDERMAN: Before we go into a linkage system involving the social security number, I would want to be quite certain that there would be very good safeguards against this kind of leakage. I am concerned about it.

MS. GROMMERS: You think that is possible?

MR. SCHNEIDERMAN: I think it is possible. I am one of the people who is in favor of the National Death Index which means tying into a social security number yet, I am very much concerned of misuses of the National Death Index and I personally need some assurance that we won't do things that can personally damage specific individuals through this kind of thing.

MS. GROMMERS: Professor Weizenbaum.

MR. WEIZENBAUM: I would just jump at your assertion here that as to a national anything, that it necessarily means he was identified through the social security number. You just stated that was an obvious fact in the world. It is not a fact at all.

MS. COX: It is not factual.

MS. GROMMERS: With that, I think we'd better go and have coffee.

(Recess.)

MS. GROMMERS: We have just a couple of things to say that went on this morning. You can be off the record for this.
(Discussion off the record.)

MS. GROMMERS: Could we, for the benefit of the record now, have our discussion continued. Now, this is the agenda, and we will adjourn from here 1:10 sharp. I promise.

There are three main things we would like to talk about in the next hour, so we have about a quarter of an hour each for bringing them up, and a quarter of an hour to distribute them for discussion.

You have all said you wanted to go and have regional hearings, for particular groups. You wanted to hear from where the subject of the files -- that's what I mean by users -- you wanted to go out and find out what the people thought who were being on these files. I'd like to hear from you what other people you would like to hear from or talk to, where you would like to have these meetings and when.

Now, what we will do here is rough it out, and if you agree, staff can organize this for us and present it back to us in August and we will get time schedules from you all for when you are free and when you can go, and preferences for where you might like to go. Then staff can do this if we give them some guidance.

The second point we would like to talk about is what other kinds of inputs to the discussion-type meeting, for example, of which Professor Pool was an example, as opposed to what is here that you might like to have, some of you men-
tioned to me that you would like to see here talked about such and such a topic, and the third point is that many of you thought we ought to get started, actually working on the draft which will be draft number six of the outline. I believe that we could at least get a certain amount of the chapters that we all agree are going to have to be in the report, no matter what final form the report takes and that perhaps staff could start to work on this. Do you all have the outline?

This outline is in my very best handwriting and represents mostly the outline that was presented at dinner last night, prepared by Gertrude and John and Jane, with all of the other people sitting around the table contributing, plus a few other things that other people that I knew who weren't at the table had mentioned to me they would like to see in the report, plus a number of items from your previous draft. This is in no way definitive or anything of that sort. It is simply a working document for a certain part of the report. One thing we all agree on, it must be done and we therefore have to get that going.

Now, where would you all like to start? On the regional hearings?

MS. COX: The first one, yes.

MS. GROMMERS: David points out that both Guy Dob and Florence were not here, and they have come to me and said that they particularly want to be sure that it is the poor
people who are definitely included in our list of people we want to hear from that I was referring to as the subjects of the files and subjects of the Welfare files, for example.

MR. SIEMILLER: On that subject, for poor people, are you talking about some of these people who are self-appointed representatives of the ghetto and poor people? Are you talking about actual individuals? I'm in total agreement. I don't have no confidence in these self-appointed representatives of people that we find in our various cities.

MS. GROMMERS: Definitely the intention of Florence and Guy.

MR. SIEMILLER: We are talking about the sharecropper and those type of people.

MS. GROMMERS: The migrant worker's child.

MR. SIEMILLER: The migrant worker's child, yes.

MS. GROMMERS: Is there a general consensus that you would all like to do at least that? Could I see at least a show of hands?

(Show of hands)

MS. COX: But I'm not really clear. Not exclusively?

MS. GROMMERS: No, not exclusively. Now, the next question. Others. Who else?

MR. DAVEY: I think some of them who are actually administering some of these systems could be spoken to. It
would be interesting to talk to some of the case workers and people doing some of these things.

MS. COX: At regional hearings?

MS. GOMMERS: Will you please make notes on these? If you don't have a chance to speak all your ideas, if we can get them today in notes --

MR. DAVEY: Well, I think at times it's been rather frustrating because in the presentations that some of the people have made, they are essentially statistical-gathering types of things. You know, they say, "That's fine. But we are really not responsible for that," and I think it would be nice to talk to some of the people who are actually on the firing line who are meeting these problems on a day-to-day basis of what are their problems.

MS. GROMMERS: Could you give us a couple of names? I don't mean the name of the person, but the title of the person you would like to see there.

MR. DAVEY: No. As far as Welfare is concerned, the case worker.

MS. LANPHERE: A vocational rehabilitation counselor.

MR. DAVEY: You know the title better than I do, but their view of the world is quite sometimes different from those of the subjects, than those of the administrators, and I have a feeling -- well, let us balance it out.
MS. GROMMERS: Could I have a show of hands? Would you all like to have some of these people there?

(Show of hands.)

MS. GROMMERS: What we will try to do is get the best mix of whatever all it is that you want, given what the constraints are of time and place.

MS. COX: I am wondering if in the regional hearings, isn't the place that we ought to try to get really down to the people that are actually, really collecting the data? We have some indication from the morning session that there is very careful control on the federal level. But do we have any obligation at all to stay on the state level or on the sample unit level? Is there the same feeling of confidentiality on protection of the individual? Because, they do have the names and all this.

MS. GROMMERS: Now, who would this be? What type of person, as opposed to a case worker or a counselor? You mean the Census Bureau data collector, the man who goes to the house?

MS. COX: I don't really mean census data. Some of the health-collecting centers or the hospitals where it is conducted in those hospitals.

MS. GROMMERS: You mean the man who knocks on the door and says, "Were you ill in the last month?" That man?

MS. COX: Well, whoever is responsible for that and
supervises that type of thing.

MS. GROMMERS: That supervisor?

MS. COX: Yes. That would involve the groups. They would have four groups doing it. It would be one of the groups that are responsible for the grass roots part of it, really getting to the people. So often, that planning above, the questions come down from there, and that group already knows from experience. They can't get answers to that.

MS. GROMMERS: Pat.

MS. LANPHERE: If I could make a suggestion here, and maybe in view of the limited time we are all going to have in these different areas, and as I suggested last night, if in these regional meetings you would pick cities where there is an HEW regional office where there is also the state office the Welfare Department, there would also be a county office or parish office in that same area where you would get at all levels from the case worker or the intake worker who first sees a client when they walk in the door, a supervisory level administrative level, and the regional HEW people who could also give you some input from their several states that they have for which they are responsible for administration as well as knowledge in their community of other organizations and so forth, that you could draw on because they live there and the know who to contact, they would have knowledge of the resourc I think you might reach more kinds of peoples at various leve
This is just a suggestion.

You could get more done in one visit if you would pick areas like this.

MS. GROMMERS: Jerry.

MR. DAVEY: May I also make a suggestion that you do one first, rather than scheduling them so quickly one after another, that if there is something to be learned from the first one that you could learn, we could --

MS. COX: At least a number of them.

MR. DAVEY: Yes.

MS. COX: You could have a couple of feedbacks.

MR. DAVEY: You get some kind of feedback on the thing then.

MS. GROMMERS: What are you talking about?

MR. DAVEY: I'm talking about the time schedule on this type of thing.

MS. GROMMERS: What time schedule were you thinking of?

MR. DAVEY: It would seem to me that before you set up the people to come to the second meeting, you would want to be functional as to how the first meeting went, because you may find that you are talking to the wrong people. You may find that you may not be getting the kind of response you want and it is a dredge for everybody involved on the thing.

MS. GROMMERS: Okay. The only trouble with that is
that --

MS. COX: Is time.

MR. DAVEY: Is the time length on this kind of thing.

MS. GROMMERS: August, September, October, November.

MS. COX: No, we can't.

MS. GROMMERS: We do have four months. But if this information is going to affect our report, it really all has to be in by October.

MR. DAVEY: I agree. I am just saying there ought to be a couple of weeks, maybe the one meeting and -- yes, fine, if that works, okay. Zap. Maybe you do five or ten, whatever you would like to do shortly after that, if it's possible. But these kinds of meetings make me nervous because you never know what your response is going to be on the other side and how it is going to work out.

MS. GROMMERS: Gertrude.

MS. COX: I still think that within this group there are enough people that have gone on site visits and have that type of experience or survey experience and that it would not be two groups, at least, because it is a different group looking at different kinds of collections of data. It is going to be done in a different way.

MS. GROMMERS: What we thought we could do -- I don't know who the "we" is -- it is just everybody I have been
talking to and --

MS. COX: A couple of them.

MS. GROMMERS: -- is staff, for example. They can overlap, and a couple of people on the committee can overlap. For example, if we have five people -- I don't know if that is the right number -- go for three days and do what we have been doing here and then two of those, plus three more go to the next one, plus either the same staff and an additional staff, I think we can build up some kind of shortening of this information exchange process that will have feedback to control what we do with the next set.

The limitation of that is that we have a lag time planning as to who we are going to invite, and we can perhaps work on that by leaving some of it flexible.

MR. DAVEY: Flexibility at this stage.

MS. GROMMERS: Because for each of them, we will have so and so and so and so, but we might add.

MR. DAVEY: You just don't want to get locked in tightly.

MR. SIEMILLER: What you anticipate is the number of witnesses that you can bring in to a hearing for a day.

MS. GROMMERS: That depends on the format. This type, I don't see how we could get more than three sets of them.

MR. SIEMILLER: At the most.
MS. GROMMERS: At the very most, I think we have to have two teams. I think it would be tiring. At least it has been, on me, to have more than one hearing in a short time period. You must have had some thoughts about that. Do you know?

MR. MARTIN: As to numbers?

MS. GROMMERS: How many people can we interview?

MR. SIEMILLER: Different categories, David, like the poor people, the research data gatherer.

MR. MARTIN: I think it depends a lot on how much advance work is done, how prepared the committee is. I think a maximum of two before lunch and two after lunch, and that may be stretching.

MS. GROMMERS: Well, if we were going to have --

MR. MARTIN: Two systems, let's say, or if you had an encounter such as Pat was suggesting which might involve people at three or four different levels starting with the intake worker and working on up to --

MR. SIEMILLER: Would you think there is any advantage in that?

MR. MARTIN: I think that might happen in a day.

MR. SIEMILLER: You can do it and say you are asking them to come in for information and we will expect that "you will be present an hour" at this and then try to set a schedule of that kind.
MR. MARTIN: You have to --

MR. SIEMILLER: In order to get the individual to respond, to start with, in place of doing too many preliminaries.

MR. MARTIN: Yes.

MR. SIEMILLER: I thought perhaps five would be a definite max on any one day's operation.

MS. GROMMERS: Five systems or five people?

MR. SIEMILLER: Five different sets of people giving you information.

MS. GROMMERS: This was a suggestion Nat made in between, not only can we be prepared as Joe was suggesting, but by our sending out a letter to them telling them exactly what we want to talk about and limit it to talking about just that.

MR. SIEMILLER: We did a big series of hearings, oh, some years ago when the Harbor and Longshoremen Safety Act was in the process, and in the works around the country, we found, as a result of that, you could get five people in if you didn't get into any extraneous issues. If you brought in over five, you are in trouble.

MS. GROMMERS: I think that you can --

MR. MARTIN: You mean if you are asking the subject of the file, as Frances was saying, to be the witnesses -- the range of questions you are going to ask them is much narrower than the people we have been dealing with and you may be runn
through more of those in a day than in the case where you are
talking to a supervisor case worker? I think it is hard to
say in the abstract how many people you could talk to.

MS. GROMMERS: And if we could work out a public
forum like ABCD which is a Boston organization, which some of
you mentioned as action minded. If we could prepare something
like that, maybe we could --

MR. SIEMILLER: Preparation will speed the program
through.

MR. MARTIN: And that will inevitably mean prepara-
tion on both sides of the table.

MR. SIEMILLER: Oh, yes.

MS. GROMMERS: I wanted to add one thing. Staff
has done a tremendous effort to prepare these things for you
all and we will try to get them to you earlier.

MR. SIEMILLER: I think they have done extremely
well. I'm going to have to get new glasses --

MS. LANEPHERE: I already have. Seventy dollars.

MS. KLEMAN: I feel if we know in advance what kin
of people we want, where you want to be, then we can go ahead
towards moving expeditiously in getting squared away, getting
the people lined up just as it is done on Hill. The Senate
and House committees have people wait, and the next person
comes along in line and then with the smaller groups, I think
things can move quite quickly. I really believe that as long
as we know as early in advance as possible, then we can do
that, having people put together these presentations in these
jobs.

MS. GROMMERS: As far as nationally, that's where
we would like to be. Now, I think we will go on to the other
You can rough out this topic and you can make suggestions to
me and to this staff and we can try to accommodate all of
these.

Now, I have some suggestions as to where you would
like to go. This is your feedback on out.

MR. SIEMILLER: It is our turn to go to Peking.
We have had two groups there already.

MS. GROMMERS: I'm with you. I am going to go.

(Laughter)

MR. SIEMILLER: It is our turn to go.

MS. COX: Let me be a little more specific. I dor
know that this is my choice, but supposing -- you know I am
very interested in welfare and that group, and I would like
first to talk to the Welfare officer that can tell me what is
going on. I would like to go with the case worker and sit ir
and listen to what she has. I mean, this is arranged, that
you sit right in there and hear what is asked and what is dor

Now, on the same day, if there was a hospital who
there was, maybe, one of the branches of the Cancer Institut
the person that is not on this level but the persons actually
operating, to go there and see how they go in and get a record out of the hospital files.

MS. GROMMERS: This is a little bit different from what we are talking about. This is really a site visit type of technique which is no reason we can't do, also.

MR. SIEMILLER: On the other hand you have invasion of a privacy of the case itself when you go in to the case worker without getting prior permission to do this. They are not used to this and knowing the type of people you are, just being there.

MS. LANPHERE: It is going to be threatening to the clients in terms of intake and et cetera.

MR. SIEMILLER: Yes.

MS. GROMMERS: We could have some types of visits within some limitation.

MS. LANPHERE: Yes. There would be instances where you could, but --

MS. COX: In some country, you actually go in with them.

MS. GROMMERS: Where would you all like to go, as far as location? Where would you like to be located?

Let me just say quickly one thing. I know you have got a suggestion about where. We can say, maybe, that five o you go to one place, Los Angeles; five of you go to Washington even on a certain set of days, so it is not one in one place
in serial and one somewhere else and --

MR. SIEMILLER: Wouldn't you like to pick geographic sections of the country to get points of different geographic views from different sections of the country?

MS. GROMMERS: Yes.

MR. SIEMILLER: Then depending upon your number, you would have six sets at match, six sets.

MS. GROMMERS: Some may want to go more than once. Some of you may not be able to go on any. So I am going to have to ask you to give us -- well, staff will communicate to you on where you want to go and when.

MR. SIEMILLER: Number two, they have offices. HEW has offices and I don't think you find regional offices in the principle cities in the ten regions. So that gives you ten cities to pick from, if that is any criteria.

MS. GROMMERS: Jim, did you have anything specific?

MR. IMPARA: Yes. There are four HEW regional office cities which are either capital cities or are in very close proximity with a capital city: Seattle being very close to Olympia in Washington, Denver in Colorado, Atlanta in Georgia, I think Boston and Philadelphia are close to Harrisburg.

MS. GROMMERS: Somebody mentioned New Orleans. I don't know whether it is a regional office or --

MS. LANPHERE: New Orleans is near Dallas.

MR. MARTIN: Well, the HEW offices in cities would
have a capacity to help and --

MR. DAVEY: We also have to think what the responses of the cities are again.

MR. MARTIN: -- then we have a lot of extra work and expense unless it can be a city in which perhaps some of the members of the committee can guarantee that the kind of backup or support, hearing facilities, contact with press -- that's an important aspect -- press facilities can be arranged in a way we can count on our regional offices to help us.

Puerto Rico.

MS. LANPHERE: Puerto Rico, yes.

MS. HARDAWAY: Let me mention a fear I have about this, and I think we can start with this. For instance, Pat wants us to come to Oklahoma. We all want to go. But I think she, on her end, would have to be very careful that she did not present to us the ideal situation. In other words, we are going to have to go and see it as it really is, not as some regional office would want us to believe that they are set up.

I know that if you came up to Tennessee, I'm going to parade you around the very best I have. I would take you to the Grand Old Opry. You'd have a marvelous time.

(Laughter)

MS. HARDAWAY: But we must be sure it is not better than it really is.

MS. LANPHERE: Everybody wants to show off their
MR. MARTIN: I didn't mean that staff would advocate the role it is playing with respect to regional office locations. It would primarily play the same role if it could happily be arranged in Oklahoma, Puerto Rico, Tennessee or wherever else, to also include a stenographic reporter and that we could prescribe what the logistics support is, maybe that could be arranged for us as it would be in a regional office city.

But the selection of who would be present and the coaching of them and all that would be done by the staff for the committee and not by individual committee members for the committee unless they want to change roles.

MR. SIEMILLER: Or actually the regional office wouldn't select it.

MR. MARTIN: No. We might seek guidance from the regional office and get prescriptions from your office and presumably we would do the same for any member of the committee.

MS. GROMMERS: As long as we didn't get too much advance notice.

MS. HARDWAY: I think this is something we should be aware of.

MS. GROMMERS: Mr. De Weese.

MR. DE WEESE: I have a small problem with dividing the committee up into two small groups, because our major
strength is our heterogeneous qualities, and I think we have
to be careful when we divide up that we don't lose that es-
pecially when we go before the public with all our resources.

MR. SIEMILLER: We are surely a heterogeneous com-
mittee for backgrounds and people and it is very good.

MR. GENTILE: Madam Chairman, I would like to make
a point concerning the subject. We are all subjects of some
file or other, and what I would like to see is something we
haven't seen yet, and that is an irate subject, somebody who
has felt that they have been damaged, whose privacy has been
invaded, and I think we should document that kind of a thing
in the hearing.

MS. GROMMERS: Didn't you have a suggestion about
that last night, how to get them?

MR. GENTILE: We talked about getting some lists
from Nader's consumer groups.

MS. HARDAWAY: Consumer groups and through Action
News, yes. I'm sorry.

MR. GENTILE: We want somebody who has really got
his back up because we are all subjects of files.

MR. SIEMILLER: John, you mean like a user of cre-
and who was --

MR. DAVEY: Who was refused credit or was refused
insurance, et cetera.

MR. SIEMILLER: Somebody of that nature.
MR. GENTILE: Someone whose privacy has been dam-
aged and is engendered against this thing.

MS. GROMMERS: Part of the trouble on what you want
to do is that it is a little premature, not that we shouldn't
do it, but just as the psychiatric people never knew they
were in the register. It is just barely now coming down. If
you sign up for an American Express card, you are getting on
the credit list.

MR. WEIZENBAUM: Mary Kay just told me -- I think
that's correct -- that if we want irate subjects, they volun-
teer because they are famous in this field, Nader, so he has
people who come in to his office with tall stories.

MR. MARTIN: Could I express one word of caution
about this? There is this sweet wonderful man by the name
of Paul Pollin -- some of you may know him -- who was the
victim, as he would put it, of a breach of the law in Oklahoma
which requires that a credit file be shown to its subjects
prior to the making of a report which might lead to the not
granting of credit. And it was violated in this case and he
has spent the last two years in his life as a professional
victim, bringing suits. His son writes articles on it and
so on. A small Paul Pollin is all you want to have, I think.

The many small victims, they professionalize their
role. You give them one sort of thing, a distorted platform
on which to perform and you are not going to learn everything
that you already know or you couldn't know if you read the last ten speeches they give.

I think it is a good idea but it is hard to get the right ones.

MS. GROMMERS: Just one more very important comment from Ms. Hardaway and then let me go on to the other two points. Then we can come back to the others.
MS HARDAWAY: For cities that have good action news type things that are tied in with local radio and TV stations, they would be an excellent source because their people are having only one go at it and they obviously are willing to have assistance or they would not have called in to the TV station and said, "I'm having this problem," and I believe they have worked with them and they would know if they were reliable or if they were professional complainers.

I believe we could get within our major cities some good suggestions on this action news type of program.

MS. GROMMERS: Which would have an advantage that we would also be building up our feedback if these people became personally interested in what we were doing.

Now, let me go on into the second section which is other inputs to our meetings and I know someone who had a contribution on that and I don't know who else does.


These are suggestions we would like to bring up to the floor on other things we would like to have come before our meeting.

Juan, do you want to say something?

MR. ANGLERO: Yes. I wonder -- and I think this goes along with what Mike said before -- it is the management systems commission, really, as such, where we get some people who give with the systems in terms of how it is to be used,
how to foster decision-making and they could decide how to control information and a lot of things.

Even I got a recommendation of some persons with whom we have dealt in the past, being in Puerto Rico, and that have been knowledgeable about some of our systems.

They have designed some of them. They are here.

If I may put in a name on the record, for example, there is Bruce Allen and Hamilton.

MS. GROMMERS: They worked with you, didn't they?

MR. ANGLERO: They have worked, but they are not working with us. It is a private business.

MS. GROMMERS: But they were helping to design systems?

MR. ANGLERO: They are designing systems for other agencies. They have made some proposals to us on how to design ours at the moment and they have even gone further into defining the planning program.

But it is in the process for Puerto Rico.

MS. GROMMERS: Which is something we haven't mentioned at PBS, Planning and Budgeting System.

MR. ANGLERO: PBS. We have a lot of things coming in from that. These people have big insights, views, also. They have done designing for PBS and PFP, Program Financial Planning, and many other things. They are a consul-
tant to HEW on one of these problems and what they do have
is a plan on just how information is needed and is used for
decision-making processes.

MS. GROMMERS: Regardless of whether he is still
doing program budgeting or planning or anything else, the
concept remains and we haven't brought it out yet.

Pat.

MS. LANPHERE: In connection with what Juan is
saying, there is another business called Community Research
Associates which does only government systems and they were
very active in designing the three-year -- well, participating
in the three-year project of CASS, Cash Administrative
System. That is what they devoted all their time to, although
their time is government systems.

We had a contract with them for a year. They had
a project with us, an excellent one.

MS. GROMMERS: And you think it would be useful
to have this kind of talk?

MS. LANPHERE: Well, they are more objective and
they have gone into all kinds of aspects; the reason for it,
what are you going to do with it, you know, for any number
of reasons.

MS. GROMMERS: What good is it for management?

MS. LANPHERE: They have worked with state, county
local, all types of governments at all levels. We found the
very productive, very useful.

MS. GROMMERS: You said you had a different kind of input.

MR. ALLEN: Yes. This is back on the point explicitly raised by Jerry and it has come up with the context of Mary Kay being in touch with Arthur -- that's what we were huddling about last night -- with respect to the practice within HEW which I think makes it highly relevant for purposes of our report to the Secretary of the existing practices by the agencies that are collecting information and the kinds of assurances of confidentiality that are in fact being given and the extent to which it is a matter of legal background which, in fact, can't be delivered, in fact, of just what the discrepancy may be in not making those who are voluntarily supplying information aware of the fact that it may be compelled to be passed on for other purposes.

I think it is a suggestion about something that would perhaps be staff studied as a report, as an input to the committee.

MS. GROMMERS: It would be staff studied, you say, or would not be?

MR. ALLEN: Would be, because of the closeness to the sources of the information.

MS. GROMMERS: So they might be trying to pull up a series of cases of systems in which confidentiality
was promised but in fact not being able to be delivered?

MR. ALLEN: Or couldn't be. Maybe you could elaborate a little on your discussion with Arthur.

MS. KANE: I think it could be put on broader terms, either regulatory or statutory, what degree of confidentiality can be guaranteed under the law that could be a support to the researcher or to the contractor, and then finding out if they are just actually giving a blanket guarantee.

Perhaps you can go to the degree that you can find out if they feel that, therefore, there was a breach because somebody could come in and legally get the data and the data subject was very disturbed by the fact that they had received a blanket guarantee.

Do they think that that is going to affect their research which the committee might then consider? Do they think of other possibilities of giving a somewhat more limited promise of confidentiality or explaining more fully to the data subjects exactly what the status of the law is, or does the committee want to take some other progress?

It is a way of finding out what the status is within HEW of the law and regulatory body information.

MS. GROMMERS: Could you make an outline, either of you? Could you make an outline --

MR. ALLEN: Yes.
MS. GROMMERS: -- of what you have in mind, or staff could find this out, also, and to what extent it can be worked on.

I suppose Jerry's comment would really have to do with this, too, what work has gone to the study if it was labeled as such. Maybe this was hazardous to your privacy for which there was a precedent.

Jerry, you had something.

MR. DAVEY: With regard to the public record --

MS. GROMMERS: Excuse me. Could we have the outline by the end of the afternoon?

MR. DE WEESE: By lunch.

MR. GENTILE: In lieu of lunch.

(Laughter).

MS. GROMMERS: Jerry.

MR. DAVEY: Coming back to this question of public record information, it seems to me that yesterday, some of the things we learned, particularly statistics that Don had, were much more about following through with respect to cases that were reported back when they were checked out and information had not been sent from the courts to the credit bureaus or to the police stations, there seems to be a real problem, and he indicated it was something in the order of 14 percent.

My guess is that it would be at least that high
or maybe even higher.

When a suit is filed in many courts of the coun-
try, there is no need to follow on, and that suit can just
be kind of dangling. It may be a nuisance. It may never
be dismissed. It is on the record and the individual who
is the defendant may have verbal knowledge of that whole
thing.

It would be nice to get some kind of follow-up
action, the same way with actions after a judgment -- I
am talking primarily about money type of things since this
is where my experience has been, in money types of suits and
judgments -- that once a judgment is a judgment for $400
to Beneficial Finance Corporation, finally that money is
paid in to Beneficial Finance Corporation.

Then that money -- then Beneficial Finance
Corporation is expected to report the fact that this has been
paid off and then that judgment has some kind of a notation
on it to that effect.

There are a whole series of reports that need to
goon to this. It varies so completely from one part of the
country to another that it is really, really fantastic.

I would like to see some information about this
type of thing because I think here is an area where very
little attention has been paid and I think the payoff may
be substantial.
MS. GROMMERS: Could we get at this by asking some of the groups that are doing this? It is an audit procedure that you are talking about, really.

MR. DAVEY: I think you ought to talk to some of the court people. I think some of them recognize it, and also recognize they don't have the budget to do it.

MS. GROMMERS: And also bring that out for the record.

MR. DAVEY: Bring that out for the record. I know there are a lot of court informed --

MS. GROMMERS: Who would be the persons we would get as opposed to hearing format?

MR. DAVEY: It could be part of the hearing format which, in New York, in my opinion, is the highest court and highest court reporting system which I have seen. They have set up procedures --

MS. GROMMERS: Would this be a court of --

MR. DAVEY: The administrative judge, or one of those.

MS. GROMMERS: One of those. Yes.

MR. DAVEY: Yes. It would be very helpful.

MS. GROMMERS: The person responsible for seeing to it.

MR. DAVEY: And maybe one or two of his chief clerks who know the problem well. You know, there's a lot
of material which we would need to know about, why it is
the way that it is, and then get their ideas about how it
can be corrected because I do not think there is anyone in
the court system who is blind to this whole thing.

I think there are a lot of people to do not re-
cognize the impact that this may have on the individual citi-
zen.

MS. GROMMERS: This might help where we could
pinpoint our recommendations.

MR. DAVEY: Yes.

MS. GROMMERS: Joe, did you have any input about
what Juan was saying?

You said you talked about it. I saw you raise
your hand.

MR. WEIZENBAUM: I am out of context.

MS. GROMMERS: This is input to the meeting.

Juan was suggesting getting some management information
systems, this type information available. Did you have
any ideas?

MR. WEIZENBAUM: I had nothing previously pre-
pared if that is what you mean.

MS. GROMMERS: No. No. I mean any other people
that you think we ought to get, any other types of people.

MR. WEIZENBAUM: Well, I made a note to myself
perhaps after you were mind reading. I wrote down the name
Russell Acoff.

Does anyone here know him?

MR. ANGLERO: Yes. He is in planning, isn't he?

MR. WEIZENBAUM: Yes. I think he is now at the Case Western Research and my impression is that he is deeply involved in planning, in the implementation of plans, has very intimate cooperation with the population about whom these plans and implementations are being made and he is an extremely sharp fellow.

He started in architecture and came up with operations and research. I think it might be an extremely great help here.

MS. GROMMERS: I think he might be.

MR. WEIZENBAUM: Do you know him?

MS. GROMMERS: Yes.

MR. WEIZENBAUM: He is a very bright guy. I will probably disagree with him, but --

MS. GROMMERS: Let me now say that if any of you have any suggestions about who you would like to have here, or in general.

MR. SIEMILLER: General? Original?

MS. GROMMERS: See what you can do.

MR. WEIZENBAUM: I have another name. There is a young lady in the Cambridge area, Brigitte O'Farrell, a very dedicated young lady, and she wanted to help, and she
said she would begin helping at the most intimate level, the
lowest level of the bureaucracy level, talking to clients,
for example.

She discovered that is not where the action is,
not where the decision is made.

She went out and went to Washington, and I forget
what agency she worked for out there; undoubtedly HEW, and
places like that. She discovered no matter where she worked,
that is not where the decision is made.

And as you cross the levels, as you get up further
the people say, "No. No. The decisions are really made lower
down."

She has been through that lower level and up and
down, and I think here experience about trying to find out the
local decision making processes, and with her experience, I
think it would be a really good thing for us to hear.

MS. GROMMERS: Anybody else? I would like to
switch over to the report. Would you write all that down and
would you also be collecting book titles that you think the
other people might be interested in hearing about, regard-
less of whether you think they may have already heard it or
not. Laymen had a copy of "Apropos of Cynicism" of which
you have got a copy, "Privacy of Information and Freedom
Act," and I hope you have seen it, "Cybernetics in the Law."

If you will bring that to our attention, we can
also circulate things like that, books. We can circulate titles like that.

Mr. Archibald mentioned to me that you might be interested in "Freedom and Security" by Williams, and we will see to it that you get a list of these titles.

MR. ANGLERO: There was also an effort made by HEW in terms of the national demonstration programs. I think Oklahoma's system is one of them and Mr. Ampara has one, and that's where the title is all in the United States and I am also informed on the Title 13 Act.

Now, I don't know what happened to it, but it was a real A-rate effort to establish in all different states a decision-making process through the commission system.

MS. GROMMERS: We will try to pick that up. Could you all look at that outline for about two minutes?

MR. SIEMILLER: Whereabouts in the outline does it answer the question if or not we should have a universal identifying number, and if so, that it should be the social security number, and if that be true, at what age should an individual be given a social security number?

And if or not there should be needed legislation to protect the use of the social security number.

MS. GROMMERS: It sounds like you are writing a checkup.

MR. SIEMILLER: To me, that seems to be one of
the most important aspects of our mission.

MS. GROMMERS: It is not mentioned on here. We must specifically address ourselves to that if we don't do anything else.

In the section of this outline under which it would come, I think what it is supposed to be is -- John, can you help me?

MR. GENTILE: Yes. I think it is covered in a number of places. Perhaps under conceptual -- should there be an identifier at all? It might be covered there.

Then under the immediate actions, recommendations covered by Secretary's Policy Statements, in that VIII.

MS. GROMMERS: I know where it was. It was in forces now working for change.

MR. WEIZENBAUM: Yes. No. 4.

MS. GROMMERS: As we were talking about it last night, that whole thing could be encompassed under -- we know how it is right now. Systems originally unlinked are starting to be linked and therefore, there is a force now working for the change of the total environment in which all of these systems we are looking at now are imbedded.

MR. SIEMILLER: I would suggest that it is a very important subject and it should not be scattered through the various --

MS. GROMMERS: Yes. It could all be right there.
However, let me say about this outline now, this is not to be --

MR. SIEMILLER: Not permanent.

MS. GROMMERS: -- not even in the order, but rather trying to pull out all of the types of concepts that in some way have to be covered and that one would be in there and why don't we put it in our outline.

Then the next question is, should not maybe staff start to prepare a white paper on that particular set of points as just mentioned for our reaction for next time?

What do you all think about that? May I hear a pro and a con and a vote?

MR. GENTILE: I think that it would be very useful for staff to start interpreting some of the things they have heard through all of these hearings and committees.

MS. GROMMERS: I want to limit it to just that one, right now, that one particular comment so we can get a closure on that. Would you all -- let me state the question.

MR. SIEMILLER: There are three ifs in the way you stated it. You have got a yes to your recommendation to the first for FDS, first, and then you have got to go on to the other one and so on.

You have got to have two yeses to the third. Let me ask the question. Would you like staff to prepare a white paper on this for your reaction?
VOICES: Yes. Yes.

MS. GROMMERS: Okay. Any pros, any cons?

MR. DAVEY: When do we have lunch, besides work?

MS. HARDAWAY: Let the record note that we are unanimous.

MR. WEIZENBAUM: Well, if that is the case, I'll go against it.

(Laughter).

MS. GROMMERS: There are a couple of things that we might get unanimous agreement on that staff has got to be working on and get them in the report and that is No. 2.

Let me read that. Listing of the types of current and proposed personal data and information systems within the terms of reference.

Then analysis of some of these, a description of analysis and interactions.

MR. GENTILE: I am for that. The staff should start writing on some of these, too.

MS. GROMMERS: For example, staff already has a listing of all the automated data systems in HEW. Whether that is going to appear here or in an appendix is another matter. But at least, somehow, we have to encompass what are all the types of systems that we are talking about.

But we, in addition, wanted to look at some private ones.
Next time, we are going to be here, if you all would like to have this, people who can talk about their--what I call the Bank and Security Act. This is the new act which took place the first of July where all your bank accounts are not going to be--and mine--I don't have a bank account, that's why--all under social security number with an automatic input to IRS for any transactions over a certain amount.

MR. SIEMILLER: $10,000.

MS. GROMMERS: And we thought we would get some people, and the California Banking Association successfully joined in a certain part of this, and we thought they may tell us where that is at, get them to come so we can get a good picture of another kind of system.

Barry Water, who was here before, was a consultant to a number of people who were involved and also knows what is going on in the electronic money process. We thought that we might bring that to your attention what is going on in this particular program which hits in the program.

It is not an HEW system. Therefore, there may be some other types like this you all might want us to bring to your attention, too.

MR. SIEMILLER: I am just a poor country boy and went to school in Florida, and I have to have these broken down, these things broken down. Excuse me.
MR. AMPARA: That's all right.

MR. SIEMILLER: And this is of their interactions. Would that necessarily be linking up with the private information that could be leaked or --

MS. GROMMERS: Any way.

MR. SIEMILLER: In any way, that would be the intent of that?

MS. GROMMERS: Yes, because anything that is informal today might be formalized tomorrow.

MR. AMPARA: Broken down. I was recording it and hardly understanding it.

MS. GROMMERS: And again -- well, Mr. Siemiller, would you -- let me put it this way. I am not saying staff is going to do all this work for us all.

MR. WEIZENBAUM: There goes our unanimity.

MS. GROMMERS: It is not going to be the exclusive group, so that none of us are doing anything either, and I really would like to know if anybody wishes to prepare a white paper themselves, and if so, will they do so?

We will put them all together and then react to them later.

MR. GENTILE: I would like to volunteer one of our members, Walter Miller and perhaps one of the attorneys in the group might want to compile or put together some model of legislation that is in existence which might appear as an
appendix to the report or perhaps anything on equipment injunctions and --

MR. GENTILE: For example, Dr. Gallati has a model of statutes here for a certain state. Massachusetts has enacted it into law. Just pulling these things together would be useful.

MS. GROMMERS: We had a model law, didn't we? The state of Massachusetts --

MR. GENTILE: Yes. That is one that Dr. Gallati was working on enacting.

MS. GROMMERS: Massachusetts. Anyway, the idea being that we will get together as much of this report as we can and we may end up saying this is what we are going to pull out of it for submission.

What all else do we need to get done? I don't know if we could volunteer our absent member, but we can certainly talk to him.

In No. 3, constraints and current legislation, is that one the staff would prepare a white paper on, or is that something we need to have more information on?

This has to do with what Arthur was asking about. What Arthur was asking about there, and that you presented really, would appear in the report, in the 3-1 category.

MR. ALLEN: I think Arthur was asking for that
No. 5 part as they bore on HEW a number of times.

MS. GROMMERS: The labeling part?

MR. ALLEN: No. The laws, the administrative regulations.

MS. COX: Currently existing.

MS. GROMMERS: Now, Mr. Gentile has worked out a matrix. Would you like to speak, sir, on what that is?

MR. GENTILE: Well, I don't want to say this is more than what it is, but what I have done was to take the check list and -- I took the check list that was developed by the staff which kind of compiled many, many of the questions that we have asked at various times and I changed them into positive statements or declarative statements and then I bounced that off against the horizontal stub in which I included vehicles for effecting or implementing those positive things that can be given.

For example, we have talked about such things as physical plants, security, lock, shredders, de gaussing tapes and that could be accomplished through a state policy bulletin or a department of HEW policy bulletin, followed up by some audit procedure, establishing custodial responsibility and justification of certain data that are collected and can be accomplished through a quality assurance in the system's development phase and so on.

So I have, across the top, the vehicles: quality
assurance for systems development, state or department policy, bulletins, executive orders, legislator, audit procedure, even data center operations manuals, the kind of policy and procedure that has been developed and submitted by the National Cancer Institute.

I thought it would be useful to just list all of these things and try to group them in the categories in which they can be implemented in some way and then to just try to wrote these policies or procedures out.

MS. GROMMERS: As I understand it, you would be willing to do some work on this personally, yourself, and prepare something that we can work with, staff on, as a white paper for the committee to react to?

MR. GENTILE: Yes. I would like to start work. This is a very big task, obviously, and I would like to start work on this and try to pull together the best that is available in other people's internal procedures, such as National Cancer Institute and then, hopefully, bounce it off the committees so it could be attacked and modified and perhaps we can have evolved from this process a sample of something that would be better than what is out here now to guide the states, for example.

MS. GROMMERS: Now, one other thing. In three, numeral 2, current communications, technology, I am going to try to get a good gem for you next time, and the other thing
is that I can ask the other computer company to bring the
computer console method that they have, to bring their con-
sole and plug it into the telephone so you can get some idea
of real communications on a world-wide survey, if you would
like that, for an intervention, but someone has to -- Joe,
somebody has to -- we need some real good work on the compo-
nets of the environ in which the systems are imbedded.

That means the current, artificial current
communications technology. Can you help us on that? Do you
have students that might help?

MR. WEIZENBAUM: As you know, I am leaving for
a couple of years and I am pushing students away and not
gathering them as such.

Well, yes, I suppose I can help and I think we
can talk about that.

MS. GROMMERS: Okay. Because, we need to gather
the latest up-to-date information for this part on the latest
up-to-date uses and what the potential is, and that also
would be in No. 4 of the forces now working for change, a
part of which is going on in the artificial intelligence
bureau and surveillance or data processing, electronic data
equipment.

MR. WEIZENBAUM: I would say; "artificial data"
is not relevant if your definition of current is "now"
and say "within 5 years."
MS. GROMMERS: Is there anything that anybody else would like to bring up right now that you feel cannot wait? If not, I would like to adjourn for lunch so we could be starting back here at 10 after 2.

If you would, be back here at 2:00 so we can really get started at 2:00.

Does anybody plan to leave early this afternoon?

MR. WEIZENBAUM: What do you mean, "early"?

MR. MARTIN: We are scheduled to adjourn at 5:00.

MS. GROMMERS: We are scheduled to adjourn at 5:00, about 4 or 5. This has to do with our order of our speakers and information you are going to be able to gain from them, and if we have to change our order because you are leaving early.

MS. COX: Right.

MR. DAVEY: What time will the break be?

MS. GROMMERS: There is none scheduled, but we are going to have one.

MR. WEIZENBAUM: I think I should leave by 4:00 for the airport.

MR. DAVEY: I'm going to have to leave at 3:30.

MR. SIEMILLER: Jerry says 3:30.

MS. GROMMERS: Well, can you all be back here at 10 after 2, then? We will have a real short lunch.
MR. SIEMILLER: Yes. Why not.

MR. DAVEY: Make it 25 to.

(Whereupon, at 1:00 p.m., the committee stood in recess, to be reconvened at 2:10 p.m. this same date.)
AFTERNOON SESSION
(2:10 p.m.)

MS. GROMMERS: Could we have the meeting come to order, please?

Good afternoon. I would like to introduce all of you to a man I have never met --

MR. SHISKIN: My misfortune.

MS. GROMMERS: -- I'm sorry to say, before the meeting, I have heard so much about him.

Mr. Julius Shiskin, the Director of the Statistical Policy Division, the Office of Management and Budget.

At his left is Mr. Joseph Waksberg, the Associate Director of Research of the Bureau of Census, and Mr. Shiskin has kindly agreed to speak first this afternoon.

Mr. Shiskin.

MR. SHISKIN: I am very glad to be here. I have had, in the last few years, some measure of improvement in my place where I do my work.

For many years, I worked with the Census Bureau -- too many to mention -- and then I moved to 17th and H Street, right across the street from the White House, and I thought that was about the best you could do.

But I think this is better, so I am glad to be here to meet with all of you.

Our office is sort of a focal point for all the
pressures that appear all over the country for data and against data, and we are almost always simultaneously struggling with people who want to do things, important people who want to do things in one way and other people in the opposite way.

For example, at the present time we are simultaneously or nearly simultaneously dealing with two Congressional committees who have very different objectives with respect of paper work.

There is a group which is spearheaded -- now, he is not the chairman -- by Senator Metcalf who is trying to weaken our authority under the Federal Reports Act.

I won't describe that authority.

But the Office of Management and Budget has a great deal of power in the statistical field and which has provided primarily, though not exclusively, by the Federal Reports Act.

Now, under this Act, we have the authority. That is, every report form that goes to the public, to ten or more members of the public, must be explicitly approved by us under that Act.

Now, the way the language is worded, I believe, is that it puts the burden of proof on the statistical agencies as they cannot issue something without our explicit approval.

Now, we don't have to explain why we approve or
disapprove.

We just have to sign.

Now, Senator Metcalf has, or some of the senators have, several, have attached to several bills a rider which would require us to make a full justification of any rejection of reform:

Now, this is obviously intended to make it harder for us to disapprove forms.

Their view, the view of some of the people there is that we make it too difficult for people to collect information. There are certain kinds of information that various groups should have, that the public should have, and through this procedure, we are making it hard for people to get that information.

So that rider, that clause -- it is not a rider, but it is a section, it is language, has now been attached to two bills we know about.

So we have got to be on the eternal watch. We were against that, to try to prevent them from weakening our position.

Now, at the same time, Senator McIntyre who is in charge of the Senate Small Business Committee, is complaining very strenuously that we are approving too many forms and putting too much of the reporting burden on business and he will be introducing a bill very shortly, he tells me -- I had
a session with him very recently -- which will try to put
pressure on us in various ways to reduce paperwork.

One of the things he is threatening to do is to
transfer us to the legislative branch, and exactly how that
can be done constitutionally, we don't know.

I, frankly, would sleep better if he did accom-
plish that, but I don't think he will.

But this is to show you the kind of conflicts we
have, always, to deal with. And I use that as a way of
introducing my major theme, which is that there are three
major forces, three types of forces involved that this group
would be concerned with.

There is one to understand in data collection
programs.

The first is that there are many important groups
in the country that have very legitimate and important needs
for information. Now, these are the people we customarily
group together under the expression "the users of data,"
who are brought in generally.

I mention this requirement first because it is
the reason why statistics are collected at all. If it weren't
for significant and important needs for information, we
wouldn't be collecting data and the other problems that I will
be coming to in a minute wouldn't exist.

So you have to start off with the acceptance of the
idea that there are certain groups of people who are very important and have legitimate uses of data, the least of these is the President of the United States, the Congress, the top policy makers of the country now, so you start with them.

Now, in order to get the information from people, there are two requirements that they impose on the statistical collecting agency, and the first requirement is an assurance of confidentiality.

The persons who provide the data want to be assured that not only is the information beneficial to society as a whole, and that's the kind of a justification we expect agencies to provide us with when they come up with a report form, but we also have assured them that the data will be held strictly confidential and not used to the detriment of the person who is reporting.

So the second point is that there has to be an assurance of companies.

Now, the third important point is that we have to make a vigorous effort to minimize the amount of reporting to reduce paperwork. Now, as you know, for the individual, reporting is almost always a nuisance.

For the business concern, it is costly. So what the statistical efforts have tried to do is utilize information that has been reported for one purpose, and for other purposes as well.
I will give you some examples of that a little later.

So you have the three different pressures. One, is pressure for information. That comes from the user of the data. Then from the respondents; they want assurances of confidentiality and they want also not to be reporting the same thing many times.

Now, our job in the statistical agencies and particularly in our office where we have control over report forms is -- and also the budgets for the statistical agencies is to somehow balance off these three different forces in an optimal way.

Now, the point I am making here is that you have to consider all of these problems together. You cannot consider one by itself.

Now, when you consider them together, you quickly see that there are conflicts among them. For example, usually, it is a relatively simple thing to assure persons who are providing data of the confidentiality. Usually, it is the grateful thing. "All right. We will make your report confidential."

We have the authority under the Federal Reports Act to insist on it.

On the other hand, that is often in conflict with the desire to minimize reporting, because if one report
is confidential -- if you assure a person that his report
is confidential, then you cannot allow other people to use
it, and that could meet duplicating reporting.

So we have these three pressures.

Now, what we have been struggling with is
some kind of a program which would balance off these three
different pressures in an optimal way. Now, I am going to
describe this program to you.

It needs a lot of discussion. There are some
very touchy issues implicit in what I am going to say and
we would like very much to have the benefit of your views
on it.

Now, I might parenthetically say that we have
gotten endless pressures from the statisticians, our
advisory committees. We have advisory committees of statisti-
ticians. We have other government statisticians to move in
certain directions, but I don't think that they adequately
take into account or they may not adequately take into ac-
count the sensitivity of the public for privacy and con-
fidentiality.

So when David Martin invited me here, I was very
glad to accept so I could have an opportunity to get a broader
view of one or more of you.

So what I think is a starting point, the kind of
things you need for a balanced program that somehow balances
off all these requirements, first of all, you have to have well established and accepted criteria for judging the needs for various statistics along with the priority scales because this has to be a very explicit thing.

When people come to you and say they need data, you have got to have some kind of a framework in which to judge these and judge the importance of these things. So that is point number one.

The second thing I think you need is a tough policy, not an easy policy, but a tough policy in approving report forms, survey methods and publication plans in the light of the needs for data.

I think considering the public pressures against reporting, we have to have a very strict set of rules under which we approve reports that are not easy.

Now, as I said earlier, that is not a universally accepted opinion. Some people think that almost everything should -- that people want to know about -- should be made public, should be approved, but I don't think so.

So the second thing is tough policy on approval report forms.

Third. I think in a tough statistical confidentiality, the law has to be very tough. Confidentiality has to be paramount, in my opinion.

Now, the law, the confidentiality rules on the
should not only protect and assure the respondent that the statistical agencies will accord statistical returns, complete confidentiality, but, in addition, the law should say that his return will be protected against court actions; for example, subpoenas, and also any other administrative actions that could be used as declarative.

Now, at the present time, only one statistical agency has a law that fully protects the respondent. That is the Bureau of Census. Their law prohibits anyone else from subpoenaing file copies of census reports.

Now, that is a very important part of their law, and the opposition -- the position of OMB has been to urge the other agencies to prepare legislation which would give their returns the same protection and try and present legislation to Congress for passing.

So we have been urging the other legislation to try to adopt the same law of confidentiality that the Census office has.

Let me say again that I think confidentiality must be paramount.

Now, to get to the next item, I will come to the fourth point, to get to the problem of duplicating reporting and the reduction of reporting burden, I think you have to have arrangements for the transfer of second data from administrative forms; that is, tax returns, data on health insur-
ance, welfare programs and so on, those arrangements for
the transfers of such data under the conditions of statistical
confidentiality described above.

Now, let me give you one example of how that
has been done in the past and the tremendous impact of it.
In the middle 1950's, the Bureau of Census made arrangements
with the Treasury Department to use the income tax forms
in the census of business and manufacturers.

That was done in 1954. Now, that was the 1954
census. That work was started and some income tax returns
were used. These were the Schedule C's which covered the
business reports.

The ones used at that time were those for business concerns without employees and it was compared to what
is done now, a relatively small number.

In the 1967 census, that was extended to other firms and, as a result, you have the following statistics.
In the 1967 census, there are approximately 4.4 million business establishments that were covered. 4.4 million.

Now, of those, 4.4 million, 2.2, or almost exactly half, came from individual -- came from tax returns. In other words, half of the people who were tabulated in the 1967 census did not have to report directly in that census.

Now, I think that is a tremendous thing. I just want to sort of get that point across. It is a tremendous
thing that half of the returns in the major census were obtained without any direct census enumeration.

Now, I worked in the Census Bureau for many years and on a very economic census and I know that in the first big month of any census, we, the top staff, spent all of our time answering letters of complaints.

Now, these letters of complaints came mainly from small business firms and those are the ones who are not reporting at the present time directly.

So this has been a very effective use of tax returns.

The program has really been an overwhelming success and has been done since 1954's census. It has resulted in savings in money on the part of the respondent, savings in money on the part of the government, and we haven't had any complaints about it at all that I know of.

So that is a very important use of administrative data and we are hoping very much to extend that to the population area.

Some of you may know that the administration disapproved the mid-decade census. The justification for that was the high cost of the census.

The mid-decade census reached a level, as we refer to, as a big ticket item and had to go to a very high level committee for approval and it was disapproved.
Now, we are hoping that through the use of the sample, the two percent sample and administrative records, such as health records, Medicare, school enrollment records and so on, we can provide a proxy for a mid-decade census more frequently.

This would be another major use of administrative records. So I think this is a crucial part of a modern statistical program.
Next, I only have two more points, so those of you who are thinking you have a chance to speak, Joe --

MR. WAKSBERG: It is a pleasure to listen to you.

MR. SHISKIN: Don't encourage me too much.

Now, third, I think here we get a little more sense of the ground. I think it is highly desirable to have arrangements for the routine transfer of a probability sample of addresses for the population as a whole from one agency to another. Let me say this again because this is a very sensitive and important issue.

I think it is important to have arrangements so that you can routinely transfer a sample of addresses, a probability sample of addresses, mind you. I'm not saying names, but I am saying addresses from one agency to another.

First of all, let me distinguish this probability sample immediately from a simple one for selected sectors. For example, if you take a sample of a certain industry, let's say you take a sample from Blacks or disabled people, then you see you are providing some information other than an address to the person who gets the sample.

But if you transfer a probability sample of addresses, then all you are transferring, it seems to me, is -- well, first of all, you are not transferring any information whatsoever about that address except the address itself. You don't know anything about that address except that it is part
of a probability sample. But you also know that if you canvass this whole probability sample, that you will come up with an estimate that approximates the universe.

Now, if we have that, you see, then the various agencies could all use such samples to make accurate estimates of the universe for different purposes. So I think it is important to have -- that is an important issue and has to be resolved and that is something I am especially anxious to get your reactions to.

Now, finally, we should arrangements also for the transfer statistical data among statistical agencies to avoid duplicate collection. This is the transfer of data themselves.

Now, this, of course, has to be done under very tight controls. For example, both agencies, if you transfer data from one agency to another, it would have to be under conditions under which both agencies have the same rights to collect the data.

Now, one thing we also have in mind as part of our long-term program is to try to get Congress to pass one or more laws which provide uniform confidentiality rules and that would help. But anyway -- further, OMB now has the right to transfer data from one agency to another under certain, very tight control conditions such as those I mentioned. That is, we can transfer data that are collected under mandatory authority, authority from one agency to another agency, providing the other
agency has the same mandatory authority to collect those data.

So these are the six ideas we have on what would constitute the kind of an overall program to balance out the needs for data, confidentiality and privacy.

Now, you will notice -- some of you may have observed that I have very carefully avoided discussing, mentioning establishment of a simple statistical agency which could do a lot of this in one fell swoop.

The reason of it is that we don't consider a simple statistical agency either desirable or feasible. We do not consider it desirable because we think a monopoly in statistical work would be inefficient as most monopolies are in terms of the needs for purchasers (?) and also wouldn't be -- the same thing in different ways -- adequately responsive.

So we think a single statistical agency is undesirable for those two reasons, legally responsive or official.

Further, we think it would be most unwise in the present climate to propose such an exclusion to this program because of widespread opposition to the concept of the idea of simple data files.

Now, I think that an outline of these points I have made have been distributed to you. They are kind of technical and there is a lot to absorb here but it is a thought out program based on statistical experience.

On the other hand, we know there are very sensitive
issues regarding various different groups, very action to it. I am here today not to tell you anything but to ask you for your reactions on these ideas.

MS. GROMMERS: Thank you very much, Mr. Shiskin.

We would like to hear first, before we have questions, from you all, from Mr. Waksberg and then the committee will have a chance to question those gentlemen.

Mr. Waksberg.

MR. WAKSBERG: Well, let me ask you a question as to how you want to arrange this. Julius Shiskin essentially spoke about the problems of confidentiality. I was proposing to dwell or to talk a little bit about confidentiality, but also about the other issues relating to statistical uses of automated data, of record keeping linkages, and I am not sure how you want to go, whether you want to go into some of these other issues, or would you rather just have me make a few comments on what Julius said relating to confidentiality and open the general floor to that discussion first? I am agreeable either way.

MS. GROMMERS: Would you like to have some questions then, first, to Mr. Shiskin directly?

MR. WAKSBERG: Let me make a few comments on confidentiality then, and then hold off on other subjects.

MS. GROMMERS: Then you will come back, is that what I understand?
MR. WAKSBERG: Yes.

MS. GROMMERS: So that may be five minutes on this --

MR. WAKSBERG: Yes. Essentially, in terms of approach, in terms philosophy, there is no difference at all between Mr. Shiskin's point of view and mine or any of us at the Census Bureau. Issues do come up though in terms of where you draw lines at various things, and one of the last remarks that Julius made I think illustrates this.

We are bound strictly by laws saying that when we take a population census, all of the information is confidential and cannot be given to anyone else. Anyone else being anyone outside the Census Bureau, and that includes the federal establishment as well as outsiders.

Well, an important issue relates to what is the definition of information? What is information? What is not? Is the fact that address exists, is this information? Is this some of the data, or is this somehow attached to it in somewhat different ways? How about a person, does his existence -- is this data or, again, or is this related in other ways?

There have not been any issues really involved in turning over anything of this sort outside the federal establishment, but there have been incessant demands on us to do exactly the kind of thing Mr. Shiskin mentioned, which is to select samples of households so other government agencies can
do their own studies and can do them independently of the Census Bureau. And most of the really tough issues that have arisen have been at sort of these marginal elements of this whole problem of transfer of data.

No one at all in the Government has ever asked us, at least to my memory, to turn over any information that we collect by the census; information on color, age. No one has asked us to turn over individual information, but we have been asked to select samples of households which means samples of addresses and turn them over to other agencies, and we have refused.

I must say that from any objective or logical point of view, this is sort of a very peculiar attitude. Anyone can walk along the streets of Washington, walk along Pennsylvania Avenue and write down an address. There is nothing mysterious about it. And the addresses we have don't really provide much more information than that, but we keep on putting ourselves in the position of telling other Government agencies if they want a sample, they have to go to what turns out to be a rather expensive process of seeking out people to Washington, to New York, to San Francisco or wherever else, to make listings of streets, listings of blocks, listings of addresses and use those of sample frame because we have refused to turn them over.

I agree from the point of view of efficiency in Government, from the point of view of, are we providing in-
formation that the agency could not get elsewhere? It is an irrational approach.

From the point of view of -- I think our feeling of the fact that we have a commitment to the people to take the definition "confidentiality and privacy" and carry it to its real ultimate extent, I think we feel at present obliged to do that. The argument is really involving these limits. There are others that are similar.

I might say that these issues of our refusing to give other Government agencies information of this sort, we treat as simply a completely one-sided affair. We are not bashful at all in asking other Government agencies for their records. In general, the other Government agencies are not bound by the same laws.

When IRS selects information on income tax, 1040s, they don't promise the same kind of confidentiality to the public that we promise, and we use the information. We use it extensively. We have been using it more and more as time goes on and we expect to use it even further. And at a later time, I will describe some of these uses.

But we have been taking a very hard nosed point of view in terms of saying that anything collected at all with any of our surveys that we have taken under legislation which requires confidentiality, anything that can be at all defined as relating to information should reflect that point of view
and this is really, I guess, the only point of which I would differ with Julius on everything he said.

MR. SHISKIN: Well, I think it should be added, also, that we have to keep this in perspective because as Joe correctly pointed out, the differences are at the margin end on the major issues of privacy, of confidentiality. We are together on that.

In fact, I think, Joe, you were quite correct on one thing.

There have been efforts to get census data in the past. In fact, in 1922, the Womens Bureau asked the Bureau of Census to provide a list of the names of women who reported. As you see, the Womens Lib hasn't just started.

Anyway, the Census Bureau refused and the issue went to the Attorney General and he rendered an opinion which said that that type of census information, that is, the names of the women, nameless women, that was information reported in the census, and that the census was confidential, and that they census data could not be distributed.

More recently, Joe, I don't know whether you are aware of it--

MR. WAKSBERG: I think a more dramatic example was in 1942 where the Justice Department asked the Census Bureau for a list of all the Japanese Americans living on the West Coast who were enumerated in the 1940 census and listed
as part of the program to move the Japanese -- to resettle the
Japanese away from the West Coast. And even under the hysteria of wartime conditions, the Census Bureau refused and did not
turn over those lists. You are right. There have been --

MR. SHISKIN: You are the last one, Joe, because it is self-serving. I don't want to be self-serving.

As late as a year ago, one of the statistical agencies asked us under the Federal Reports Act to help in -- use our authority under the Federal Reports Act to help them get certain data that were collected in the 1970 census. And as fast as you can say Jack Robinson, we refused to do so.

So I want to emphasize that we, like the Census Bureau, consider the data collected in the census confidential. Confidentiality is paramount.

We do run into questions at the margins, but they are important questions for the successful operation of the decentralized statistical system, and that is why we are pulling them in.

MS. GROMMERS: Thank you very much. I think what we will do is have some questions from the committee for Dr. Shiskin. Would you like to start, Ms. Hardaway?

MS. HARDAWAY: Yes. Mr. Shiskin, I will ask, when you refused to give that information a year ago, was that by an administrative decision of your own, or were you strictly going by your administrative decision?
MR. SHISKIN: Well, they came to my office and the asked us and that was a very easy decision to make. We knew what the law was. We knew the confidentiality provisions of the census and it seemed very clean-cut. We had no difficult on that at all. We just straightforward said, "It is against the law, against the decision of the Attorney General and the answer is no."

MS. HARDAWAY: Thank you.

MR. WAKSBERG: I would gather from your question, you sort of implied what if somebody else had been --

MS. HARDAWAY: Yes. Yes.

MR. WAKSBERG: If Mr. Shiskin or anyone else had reached a different conclusion, it wouldn't have made any difference because the Census Bureau would have refused to do it in any case because we would have been breaking the law.

MS. HARDAWAY: Thank you.

MR. DE WEESE: I'm going to pass.

MS. NOREEN: On these sheets that you gave us, you mentioned that a tough policy is geared toward confidentiality. I was wondering what you would consider a tough policy.

MR. SHISKIN: On confidentiality?

MS. NOREEN: Yes.

MR. SHISKIN: Well, what I think is a tough policy is the one I just enunciated: no information collected under
conditions of confidentiality can be transferred to anybody at all outside the federal establishment. They can be transferred to others only under certain circumstances such as those described in the Federal Reports Act which is as follows:

-- now, let me describe this experience which was some years ago. This was after World War II.

The office of Emergency Planning asked the Census Bureau for the names and addresses of certain manufacturers and certain information about those manufacturers. Now, they themselves, the office of Emergency Planning, had the same authority as the Census Bureau to collect those information and they would have gone out and collected them.

Now they, also under the law, had strict -- were required to maintain the same kind of confidentiality as the Census Bureau.

So my predecessor in this job directed the Census Bureau, under the authority of the Federal Reports Act, to transfer that information to the OMB, and that was done. So I think this is consistent with the strict confidentiality law.

Now, you come to this point that Mr. Waksberg and I have been touching on, the transfer of addresses. Now, the: I don't really know, I am inclined to think, personally, that if it were up to me and I had to decide all by myself without worrying about any outside reactions or laws, I would conside:
a probability sample of addresses as not confidential.

But this is such a sensitive issue that we wouldn't take that position without extensive consultation and, perhaps in the end, we will have to go through the Attorney General for a ruling.

So I guess what I have done is to try to describe what I consider to be a clean-cut case of transferring data under conditions of strict confidentiality and a marginal case.

MS. GROMMERS: Mr. Shiskin, we have a question from staff that I would like to address to you.

When Census and OMB have a dispute over the transfer of information, who ultimately decides? And must it be referred to the Attorney General, or is there any other avenue

MR. SHISKIN: Well, let me say that the marginal returns -- I would like to start this off with a preparatory remark that I was at the Census Bureau for 24 years. But the marginal returns many times have been greater in the last three years than any three years of my life, and the reason is that I am dealing with the top policy people in the Federal Government.
One of the things I have learned is that within certain bounds, you know these questions depend upon a power structure, and if there were an issue like that and it was clearly to the interest of the government to get the data transferred and the head of OMB was in a much stronger position than the Secretary of Commerce, the data would be transferred.

So that is the real world.

Now, let me come to the theoretical world. You see, that was the real world.

Now, if we really push this issue and Mr. Schultz thought it was best to move the data, I think the data would have moved. That is my opinion.

Now, of course, there are other avenues and that is the press, Congress. There can be a fuss, but that is the way it can go. That is the real world. But we don't want to do those things and we don't.

Now, what has happened and what can happen and what could happen is that the Census has possession of the physical data, not OMB.

So if we direct them to transfer the data, you see, then we can use this power. But we don't want to do that. Generally, it is rare that we do.

So what we would do is go to the Attorney General and ask for a ruling. He would have to, just as the Women's
Bureau in 1922.

So that is the course you can go, too.

MS. GROMMERS: Thank you.

Professor Weizenbaum.

MR. WEIZENBAUM: I am a little puzzled now of what I heard about the real world but we don't want to live in that world. It is enormously puzzling to me.

MR. SHISKIN: Let me try to clarify it, that is, if you are finished with that part of the question.

MR. WEIZENBAUM: Let me clarify my puzzlement to you. I understand about the real world and the not real world, I think. It would suggest that you ultimately rely on the President, that is, if he put the Secretary of Commerce in a more powerful position, then the Secretary of Commerce could exercise more leverage and could get it done and things of that kind.

My impression is that if the Bureau of Census doesn't want to give the information in the real world, it isn't going to be given even if the Attorney General says it is to be given, like a great many orders given in the government which were not obeyed by the Civil Service.

However, I am puzzled about that. I think we could spend a day on it and it is fascinating. I am sorry we opened it up.

MR. SHISKIN: Let me make one or two more remarks.
I guess I didn't put that well.

What I had tried to say is, well, it is a power structure and there are a lot of things under the structure, particularly these marginal situations.

We professional civil servants do not like to do that and we do not do it, you see. What we try to do is follow an orderly process and that is what we do.

That is, so that we could use the route to go to the Attorney General in this instance.

Now, I would like to say that that is not a simple thing as it sounds, either, because for one thing, my experience with the Department of Justice is that they are extremely busy people and they often do not have the time to do the kind of research that really should be done in connection with these problems.

I very recently have been talking to some of them about this issue and they work on issues here for one day or two, and then they go on to something else.

I am sure that there is no attorney in the Justice Department who understands the implications, the sensitivities of these problems as well as Mr. Waksberg and I do, and yet, they are the ones who would be doing the ruling.

There is one other point, which is, if an Attorney General -- if the decision comes to the Attorney General, this could get into the press and into Congress and you cou:...
have a trial not on an issue -- not on the merits only, and
you could have a big debate and in the press before the issue
is resolved on the sensitive issue.

I do think it is so important. It is so important in resolving these issues as to not only have very
thorough discussions among ourselves but to deal with people
on our own statistical policy, which incidentally includes
eight past presidents of the American Statistical Association.

It is sort of a round-the-table discussion of
the profession. So we have had long discussions with them,
but also with groups like this one so that before the issue
goes to these great units of power or gets involved, goes to
even the Attorney General, we would like to have all this
thought out, all discussed fully with knowledgeable profes-
sional people in the field.

Does that help in any way?

MR. WEIZENBAUM: Yes. Thank you.

Let me get to some perhaps less fascinating
questions.

Two major points you made, one was -- to quote
you -- you talk about this and said confidentiality is
paramount, in your mind. That is a very big word, paramount.

You also talked about the necessity to demon-
strate the need for the information if one desires to collect
I have two questions about that. One is, how is that need
in your survey, how is or how ought that need to be jus-
tified?

That is, for example, if somebody says three times
that "I need it and I really need it," is that a better jus-
tification than saying it just once?

Secondly, I happen to agree with you as to the
need that it is of a paramount nature, the confidentiality.
But I am interested in asking you why you think it is para-
mount?

MR. SHISKIN: Why I think confidentiality is
paramount?

MR. WEIZENBAUM: Yes. So there are two questions
here. One is how is the need demonstrated, or how ought it
to be demonstrated to you? Secondly, why do you feel that
confidentiality is a paramount issue?

MR. SHISKIN: Well, let me take your questions
in order.

I think that in order to demonstrate need, we
have to start off ourselves with a priority scheme for col-
ection of data. Now, we have such a scheme. We have
developed it and it is published. It was published in last
year's budget and possibly the one in the year before.

We have listed what we think are the most im-
portant data requirements, you see. Now, the first single
most one, the first on all of this is the need to improve the
Now, the reason I say that is that I know from direct personal experience that your GNP figures into, directly, decisions on major economic, financial -- monetary financial policy decisions.

So --

MR. WEIZENBAUM: Excuse me. A question back there. When you say "need to improve the GNP figures," you don't mean to have them grow but need to have them precisely?

MR. SHISKIN: What was your question?

MR. WEIZENBAUM: When you say "need to improve the GNP figures," it sounds like we have been growing them more than ever, not exactly --

MR. SHISKIN: Well, for example, the retail scale makes up 30 percent of the GNP on the opposite side. Now, we have got to have very accurate statistics.

MR. WEIZENBAUM: I see. So it is economic management you are talking about?

MR. SHISKIN: So we have a whole scale like that and they have them scaled and I am sure there are disagreements on what our priority scheme is.

Other people have them, but we do have them, too.

Now, social and program statistics are in that scheme, so we have that.
Now, when a form comes to us, we review it in the light of those criteria, and on the form itself, we have on the form itself the proposal to us, the commencement of requirements for filling out the form, how much time it will take for the respondents to fill out the form.

So we have certain data that were inadequate but it is not an aimless process in answering your specific question that 80 times is any better than saying it once.

Now, to get back to this real world issue, I wouldn't deny that a lot depends on who says it, too. Sometimes we have to go along with these people that we don't like to go along with.

Further, you run into this kind of a situation. We just ran into a major problem that has led to a very large amount of reporting from businesses.

Last year, Congress passed a law on occupational safety and health. Now, this law requires very detailed record keeping on the part of every establishment of the United States and has led to a very large increase in the record keeping and reporting burdens and we are getting an endless amount of complaints about that.

Did we get this from the business community?

Now, our answer to that is that there is a law on the books. The law was passed by Congress and signed by the President. We can't use the Federal Reports Act
to countermand a law when the Justice Department comes to us with a request for forms to get that information.

We can try and simplify the questions and somehow use our expertise in improving the form of the questions and things like that. But we have got to improve the form.

So this is a way of answering your question.

We do have these criteria. We do require not only justification in terms of explanation from these people who are proposing the form, but we also require them to provide us with a statement of the number of manhours required by respondents to fill out the form.

We recognize that laws have to be observed and we are first to observe them. So these are the kinds of an atmosphere in which we review the forms.

I understand, by the way, that Roy Larry who was on our staff was here and he discussed some of these problems.

Well, I think confidentiality and the privacy are paramount. I enter a more philosophical ground because, you know, in a free society, I think the rights of an individual are extremely important.

We have to observe them, and when you go to him for information, I think you have got to make a bargain with him that you are not going to tell anybody. So I think this is just part of our kind of a society.
I might tell you of a very interesting interchange that took place a month ago or so at the Conference of European Statisticians which I attended in Geneva, and I had the great pleasure of meeting David Martin on the plane, spent half the night talking about these problems.

I still haven't recovered. You know, we had a very interesting exchange and I think it might be worth your time for me to tell this little story.

This issue was on the agenda, the Conference of European Statisticians. The Conference of European Statisticians is one of the regional bodies, regional committees of the United Nations Statistical Commission. There are several such, agency groups: African groups, European groups, we belong to a European group and it is a very good group of people who try to get together the top statisticians in Western and Eastern Europe.

Now, this subject was on the agenda, and as a paper prepared by Tom Lyndon of Ireland on the subject, that was a basis for discussion, and that paper will be published in the August issue of the Statistical Report and some of you may -- oh, I guess it has been distributed, so you already have it.

MS. GROMMERS: We would like to have copies.

MR. SHISKIN: Well, David can get those for you but I think you already have them.
MR. MARTIN: They have been distributed.

MR. SHISKIN: At that discussion, it is very significant that only the Western European countries and the United States spoke. The Eastern European countries did not participate in any discussion in full. It was a very lively discussion and went on for three or four hours.

We just sort of cried on each other's shoulders of all the kinds of problems we had -- by the way, more in Europe than here.

Well, now, the way those meetings operate, or work, is that before any meeting closes, usually three or four days -- this one lasted a full week -- there has to be a completed report.

Otherwise, of course, there would never be a report. We couldn't get it out in time.

Now, when we were reviewing the report which the Secretary prepares at night, by the way, for each day's meeting, there was one expression in there as follows.

It was generally agreed that enumerators for the Census should be selective and from neighborhoods outside the enumerated area.

Now, we all agreed to that. The U.S., the Danes, the Swedes, the Irish and so on and so on. And it was just agreed to. But during the discussion of the report, the Russian delegate objected to it. He said he did not agree
to it. He did not speak to it at all and the other -- all
the other Eastern European representatives expressed opposition to that statement and what they explicitly said is that
they think the enumerators should be selected from the
districts in which they live, that is, they should be coming
from those districts because that is the only way you can
assure accurate reporting.

So you see, I come back to this in that I think
in a free society like ours, you have to give your people
that confidentiality.

MS. GROMMERS: I think we'd better go on to
the next question, because we have to finish it at 10 after.

Mr. Gentile.

MR. GENTILE: I have a few questions.

Number one. Within the past one or two years,
the governor of Ohio wrote or signed a 65-paged letter to
President Nixon listing all of the various reports that are
required by the federal government for states to respond to,
and you mentioned earlier that you accept as an axiom that
the people who have the need use it and they come to you and
you go out and approve their forms.

My question is, how did OMB -- I assume -- OMB
got that letter for response -- how did OMB respond to that
letter?

MR. SHISKIN: I was involved or our office was
involved in it.

I didn’t do it, personally, but one member of my staff worked on that and I am not sure I can report accurately. But just what I can conclude is that we did respond to that letter and you could get that response and I could find it for you later.

But let me see if I can dig out in my memory where we came out on that.

First of all, we thought the government had a legitimate complaint that we had not done a good job in reviewing those forms, and we set up a task force to take another look at it, and I believe that we have cut out a substantial amount of the reporting required from the states.

In general, we have not done a good job in the past in reviewing forms that were required from states. I think if my memory serves me correctly, we found a lot of -- what he was reporting was time spent by a state employ well, my memory doesn't go that far.

But, in general, we found out he had a good point and we tried to clean it up and we don’t really -- well, we do it but we don’t do a perfect job.

MR. GENTILE: Can I conclude from that that you did not accept as axiomatic anybody that is submitting these forms actually have a need and a use for it? It is not a
matter of forms design?

MR. SHISKIN: Certainly not.

MR. GENTILE: It is a need for the data as well which gets you into their program areas?

MR. SHISKIN: Well, we have got to be careful there, you see. We don't want to use our power in the Federal Reports Act, through the Federal Reports Act to review needs for programs.

Now, suppose there is a program that has been agreed to, congressional laws as I have said before, and some statement of some agency wants a program.

We are not going to hold it up, so their program -- just because of our authority to collect data. So in general, when an agency has a program in accounting, we will axiomatically accept their program.

We agree to have that program, a program. However, we reject a great many forms.

So it is clear that we don't axiomatically accept the statement of any data as such. I want to add just one point to that statement I just made.

If you will look at our records, these are the records that all Larry keeps. You don't find many forms rejected because it really comes to this point. It really comes to the point that the agency comes to us with a form and we reject it.
Well, what happens is that when the agency wants to get information, we look at the form and we talk to them and, most of the time, when either the agency doesn't need the data or it is collected by somebody else, they withdraw the form.

But there is no data -- we have a big impact on form collection, though. There are many areas where we don't do a good job.

MS. GROMMERS: May I go on? I think we have to have a chance for everybody to ask Dr. Shiskin and Mr. Waksberg a question.

May I ask you both just to give an absolutely shorter response so everyone gets a chance for their brief meetings -- questions?

We hope to get you back very soon.

Mr. Davey.
MR. DAVEY: Yes. Let me go through a sequence of events and I would like your counsel on this which raises the whole issue.

Assume I am in a particular agency that would like some information from income tax returns and using your point IV or point V, say it would be useful to have for something or other, and use address information or something of this nature, then this information would be transferred to this other agency. And now, this agency, because of its nature, is not able to protect the data as completely as maybe Internal Revenue Service would be able to protect their data and someone is aware of this type of a study and comes either through the open end information action or subpoena action or something like that and wants to get this information and somehow or other gets this information using the address as some kind of a key and as they will tie that address into, say, a situation where you go into a city and get one of these directories, street directories, and be able to match up the names quite readily with this address -- now, I think I covered a number of issues that are maybe bothering us -- but could you comment on these?

MR. SHISKIN: First of all, I should have made it clear that under the Federal Reports Act, we do not have authority over tax forms at all.

MR. DAVEY: Take another agency then.
MR. SHISKIN: That is a very big issue because the tax forms represent a large percentage of the reporting and one of the things Senator McIntyre is trying to do is change that so we would have authority. Also, of course, let me remind you that he wants to transfer our function out to legislative or executive branches and -- well, so the Secretary of the Treasurer has to do that.

Now, we happen to be involved with them right now in such an issue and he and we insist that when this authority is granted to another agency, that they establish strict rules, strict confidentiality rules, at least as strict as IRS.

Furthermore, the Secretary of the Treasury has been insisting that the other agencies demonstrate that they have appropriate physical facilities to protect the forms, you see, against criminal acts. It is one thing of confidentiality, but there is another kind of problem that people still face, including forms. So my view is that when a form gets transferred --

(Inaudible due to noise interference by microphone system.)

MR. SHISKIN: --strict confidentiality when the census is prepared itself. Is that responsive to your question?

MR. DAVEY: A bit. How about the situation where somebody comes and says -- I forget the name of what we talked about yesterday. Freedom of information?
MS. GROMMERS: Public information.

MR. DAVEY: Public information -- and comes and says, "Because it is in this agency, I would like to get information." We were also told yesterday that many promises of confidentiality cannot really be honored because the people who gave the promises of confidentiality were not able to give that promise.

MR. SHISKIN: I think that's right. I think that's correct.

MR. DAVEY: It is a kind of situation of where we are now, this kind of situation.

MR. SHISKIN: Where we are -- I think you are absolutely right. You will recall, 15 or 20 minutes ago, I said the only agency in my judgment that has appropriate satisfactory confidentiality was the Bureau of the Census.

Now, our response is that we are urging the other agencies to get their attorneys to draft similar legislation and try to get Congress to pass it. We will support it.

Now, what is going on at the present time is that many agencies who do not have that authority that the Census has are forced into the position you described and those people have no business making those contacts and in essence shouldn't be making those contacts.

One thing we do under the Federal Reports Act is we insist that when the agencies write a law, establish the
form, make it clear whether the form is going to be confidential or not, and we also look at their confidentiality laws.

Now, in general, I think the confidentiality laws leave a lot to be desired. What we are hoping is that we can get a uniform confidentiality law passed for all physical agencies.

Now, I gather from our attorney, we cannot have a single law passed that would do that. Each department is to get their own law. But again, let me say that the only law I consider satisfactory is the Census Bureau.

MR. DAVEY: I'd like to continue but will give up my time.

MR. SIEMILLER: You used it.

MS. GROMMERS: Would OMB issue a better confidentiality law for IRS as well as --

MR. SHISKIN: I can't speak for OMB and IRS and all its ramifications.

But in terms of IRS -- let me answer your question this way -- that we would like to see the census law be, in effect, legal through Congressional action for all agencies' publications in existence including the IRS statistics.

For other than the IRS, I don't feel I can speak for OMB.

MR. DAVEY: How about in the meantime, what do you recommend for civil laws such as these if passed during this
interim period, assuming that laws can be drafted and passed?

MR. SHISKIN: Well, first of all, as I said, we are
urging the agencies to take a look at their laws and then,
secondly, I guess what I recommend is that they should not
promise more than they can deliver and they should make it
clear to respondents that we are insisting on this. We are
having all sorts of problems because -- we have had a major
problem, for example the water pollution this year, where the
issue -- and some of you may have heard changes about our
holding up a pollution form for seven years. Well, it is true
that the dispute went on for seven years and we did go on for
seven years and the reason why is that we insisted that the
Interior Department make it clear that the respondents were
not being promised confidentiality. That was the issue, and
we wouldn't approve the form until they did make it clear.

So my answer to your question is that we insist
that agencies do not promise more than they can deliver and
make clear what they are promising. But that is in the inter-
im, maybe, and I haven't thought about it, myself. But the
main thing is to get confidentiality laws on the books.

MR. GENTILE: Can some of this be accomplished by
federal regulations that are within the rights and authorities
of OMB since it is the OMB now that has the management and
responsibility?

MR. SHISKIN: No. It is a Government of laws. It
is a Government of laws. You have got to get the laws on the books.

Now, if an agency doesn't have a strong confidentiality program, then they can have an administrator ruling on that. You see, many agencies have that, but that is not as strong as the law. I don't know about that, if that gets challenged under the Freedom of Information Act.

But there is even another kind of situation. Suppose a Congressional committee comes in, the federal agency, and says, "Look. I want to know what this man is doing."

The director of the Census would certainly say, "I can't tell you."

But a man who has based it on administrative regulation, I don't know if he could get away with it.

So I think you have got to get the laws in the books. That is my answer to that.

MS. GROMMERS: The next question is from Ms. Cox who is past president of one of those Brahman organizations we were speaking of.

MR. SHISKIN: I am aware of that.

MS. COX: Yes. I served on that committee until --

MR. SHISKIN: Did you resign or did you --

MS. COX: I resigned, finally. I resigned, finally, from it. Well, let's don't say why.

I would like to pass and have an opportunity after
some of the other agencies, besides the Bureau of Census, have made their comments because mine applies across the board.

MS. GROMMERS: All right. I would just warn you that some people may not be here. That is the only problem, and in light of that further information, would you still wish to pass?

MS. COX: Well, I don't know. I will just ask the agency I refer to to excuse me. I am serving on the committee. I know that constantly we were trying to avoid getting duplicate information and various agencies getting duplicate information. But this sort of leads into the linkage question and how much of that linkage is being done.

I read memorandums and I get an impression that much more linkage is going on than I had realized.

Now, the Bureau of Census has strict confidential rules. They have to make certain commitments.

Supposing another agency similar to the National Center for Health Statistics feels that they have to give their people a promise of confidentiality, you are giving me some doubt as whether they can back that up or not. But they never would get a lot of this data if they didn't promise confidentiality. But interagency wise, you allow a census office to have IRS -- or some of these others, welfare data -- I'm coming back to the right of the individual -- the Census makes a
commitment, the National Center for Health makes a commitment, and you see no difference in interlockings. Is the individual notified when they give the census information that this is confidential for census purposes?

The other agencies make it clear it is confidential for their use, but does the individual know when you use it for some other purpose that has linkage?

I mean, there is a code of ethics we talked about. The individuals have a right to know that it is not only being used for census but it is being used for welfare, for internal revenue, and what protection does the individual have, and do you have an obligation to get permission from your individuals before you pass it on to other agencies? Because we know as soon as you begin to link, even though it is to what you call statistical group data, that you are losing confidentiality as soon as you begin to cross over these very sensitive medical records and you have it by regions, you have it by areas, and you it broken down into your census divisions -- all that, that you lose confidentiality. Both of you lose as soon as you begin to cross it and everybody has the right to know that.

I mean, we have talked about a code of ethics for the individual. Now, you instruct on what the law says, that it must be confidential. But unknowingly or just by your linkage, your discipline, do you --
MR. SHISKIN: Well, Dr. Cox, I don't know who you are addressing this to.

MS. COX: Well, the Bureau of the Budget, really, and Walt Simmons over there. Of course, you may be the one that this is addressed to because it is the Bureau of the Budget -- it was the Bureau of the Budget when I was on there -- that tries to get this interlinking and we are always trying to get certain things done by the census and other things by the action agencies.

MR. SHISKIN: This is a good issue, and one of the other things, Madam Chairman, that has failed to take place in the last hour is that the committee has been asking me questions but they have not given me any advice. I thought there would be some exchange here.

MS. COX: Well, you can turn this around.

MR. SHISKIN: What I talked about, I would like to know what you think about this.

MS. COX: It is only the way you look at it period. You can turn it around and look at it.

MR. SHISKIN: Let me say this. The conditions under which we have transferred data in the past -- and we have used this authority very sparingly -- we have --

MS. COX: I understand.

MR. SHISKIN: A lot of things take place without our participation, sparingly, but the conditions under which
we have done this have either been one of the two things; one is that both agencies have the authority to collect information.

MS. COX: They have the same authority about collecting different data?

MR. SHISKIN: No. No. No. My point is that well, right, but let me come back to the case that I know of. The OMB office of Emergency Planning, they intended to go out and collect, under mandatory planning, data that were already collected by the Bureau of Census.

MS. COX: The same data?

MR. SHISKIN: The same data. And we said, "Don't go do it." My immediate predecessor said that, and I agreed. He said, "Don't do it." And he directed the director of the census to transfer the information.

MS. COX: But he took the census -- he didn't get any additional data?

MR. SHISKIN: No.

MS. COX: Then that is not linkage.

MS. GROMMERS: Pointing this up a little bit, I think what you're referring to is a joint responsibility. Once OMB has agreed that there be linkage, which if they didn't do wouldn't be possible, then indeed there is another kind of obligation that follows. Is that what you are saying?

MS. COX: The individual has given the Census
Bureau -- under, one, confidentiality -- a use and they have not been told that it is going to be used under another condition for other information purposes.

MR. WAKSBERG: Well, using the term "census" is probably an incorrect one because we have not turned any information over for purposes of linkages or anything else. But you might refer to some other agencies and this is possible.

MS. COX: But now, wait a minute. He just got through saying that they took your data, this special case.

MR. SHISKIN: We directed the census --

MS. COX: And to give him the data. They are using it for a different purpose than you collected it for.

MR. WAKSBERG: I thought you had reference to linkage, bringing two sets of data together.

MS. COX: Well, we have got off on another subject because he made the example another one. Now, I don't know how much the National Health Statistics uses data, census data as a tie, but you use IRS.

MR. WAKSBERG: This is the same data. We use other information.

MS. COX: Well, I made my question to mean where I used IRS and the other have made confidential commitments which is not needed, and now you are using it for a different purpose.

MR. SHISKIN: I think that is a good point. Right.
Right.

However, let me say this. It is a very difficult issue and I hope it is the kind of reaction we need and that we can get from you as to what is the sensitive issue, where should we be careful?

What I can't say in this context, in this particular case, is the following. Some of you may know that we have a business advisory council on federal reports. This is an organization which tends to go throughout the whole business community.

Now, we have discussed this, the use of tax returns with them, and they support it. So I think we can say that while we have not informed the individual, 2.2 million concerns in the 1966 census that the tax returns were being used in the censuses in view of direct reporting, we have discussed it with official business representatives of those 2.2 million people and, in general, they support it.

MS. COX: But I might be very unhappy to know that the income tax reports go over to the census people and that's what they use.

MS. GROMMERS: Would it be possible -- I'll just ask the question for you, too, if you know -- that the confidentiality comes by IRS and is not able to be backed up by law, and for you to require -- if someone asks you if there can be a linkage -- that this linkage be stated on a form, if
as you control the forms?

MR. SHISKIN: Well, let me tell you about a recent survey that I had a direct role in. Joe knows a great deal about it, too.

Under our authority, we directed the Bureau of Vital Statistics two years ago to make a contract with the Census Bureau, for the Census Bureau to collect the data under the Consumer Expenditure Survey. This was no small thing.

The Consumer Expenditure Survey is the biggest survey in federal statistics outside the fixed census or the population census and it is a very major step. And I might say that everybody involved objected to it, both the Census Bureau and the IRS.

Finally, they both reluctantly agreed, up to at least a few weeks ago, and I don't think there would be lesser evidence of it now, although they are happy with the quality of the responses, as we thought in the first place, because we thought the Census Bureau did the job cheaper.

MS. GROMMERS: To answer my question, would you be able to -- whether you want to is a different matter -- would you be able to require that this be put on the form?

MR. SHISKIN: I don't know exactly what I did or what Dr. Brown did, the director of the census did or others did, but what happened as part of this program is that Dr. Brown, under his signature, wrote a letter to everybody in
this probability sample of addresses and, he told me he ex-
plained to them in a separate letter, he told them, you see,
that the data would be collected by the Bureau of the Census
for the Bureau of Labor Statistics under the authority of the
Bureau of Labor Statistics law, and that these data would be
held strictly confidential and seen only by the Bureau of
Census and BLS employees.

Now, he wrote them a special letter and made that clear.

Now, there are also statements on the form to that
effect, but I don't remember that. But I do remember very
clearly that Dr. Brown's letter.

So in this case, we did exactly what you suggest,
and I think it is a very wise factor.

MS. GROMMERS: Could you put it on the form? Could you require it be on the form?

MR. SHISKIN: I think it says so on the form. I don't remember. I don't have the form with me, but I think it says so, I mean, in general.

MS. GROMMERS: In general.

MR. SHISKIN: Oh, we could certainly require it because nobody could send out a form unless it has ten or more numbers, and I think we do. I think we have the form. Do you have it?

MR. WAKSBERG: I believe so.
MR. SHISKIN: I believe it is on the form, but it is crystal clear that in addition to the form itself -- by the way, in this form, the respondent doesn't see the form. He doesn't see it because the enumerator has the form.

So to get around that, we had a letter mailed, signed by the director of the census explaining that to him. By the way, it is a very interesting situation there because as we anticipated, and I think the census people shared our optimism, they were reluctant that they got the job. The response was very, very good, certainly responsive than what the BLS got on 1960.

MS. GROMMERS: You are certainly giving us some excellent ideas on what kind of advice we might be able to give you.

Let me go on to just get on the floor for the record the questions of these other four gentlemen and we hope very much you are going to be coming back and talking to us, too.

Mr. Siemiller.

MR. SIEMILLER: I will pass.

MS. GROMMERS: Senor Anglero.

MR. ANGLERO: Well, I've got just a couple of simple questions. As you mentioned before, you were in support, in favor of the establishment of a central statistical agency.

MR. SHISKIN: Right.

MR. ANGLERO: Would you hold the same view if we
talked about a statistical library and such as that instead of a central federal agency, which could be a state or local level?

MR. SHISKIN: Well, I really don't understand the question. What do you mean by "library"?

MR. ANGLERO: Well, a place where all the statistics could be governed, not having an agency to collect all information but just to be available.

MS. GROMMERS: Is what you are referring to a depository of records?

MR. SHISKIN: Individual records?

MR. ANGLERO: No. Statistical.

MR. SHISKIN: You mean books or tables?

MR. ANGLERO: All the information that could be available to the public, instead of having it in different agencies, to have it in one common place.

MR. SHISKIN: Let me make sure I understand. Let me say it this way.

If you talking about bringing together statistical tables prepared by many different agencies, certainly, I would support that. I wouldn't oppose it. It depends on whether it is useful, but I would find that I have no objection if it is obvious it is a good thing to do. But if you talk about bringing together individual records, I am opposed to it.

MR. ANGLERO: On statistical information?
MR. SHISKIN: Why should I object to that?

MR. ANGLERO: Okay.

MR. SIEMILLER: Operated by the Congress.

MR. ANGLERO: On the other hand, would you assist us about the need to collect or gather or accumulate personal information on a central federal level?

MS. GROMMERS: How important do you think that would be? Would that be a good idea?

MR. SHISKIN: To do what now? I don't understand.

MS. COX: Personal data?

MR. ANGLERO: To have -- I don't think I exactly put it as you did. Let us put it this way.

We know that different agencies, even programs in the same program, gather in personal information and keep it at just the collectors and reporting sublevel. But some other agencies do collect this information, personal information and bring it to a level.

MS. GROMMERS: For example, a state's statistical level?

MR. ANGLERO: Well, I can say state's vocational, which is one I know. I can quote some others and also social security. Okay? I'm just asking in terms of the need to do it that way, to have it at a central level, this personal data, personalized data.

MR. SHISKIN: Why should -- let me see if I can
understand your question.

Why should the Social Security Administration, for example, find it necessary to bring all the social security data in one place or can they be centralized?

MS. GROMMERS: Do you think it is necessary? Is there any reason for it?

MR. ANGLERO: Yes. You see?

MR. SHISKIN: Well, I don't know. I think you would have -- I would have to look at each program separately and make a judgment on it, and I would be reluctant to answer that question.

MS. GROMMERS: Do you want to give us an example of what you want?

MR. SHISKIN: I think I can understand the general principle, which is the following. We faced this issue a little more than a year ago because we instituted at that time a major reorganization of federal statistics and our reorganization plan provides for the establishment of six to eight statistical centers, not one. So there would be six or eight separate statistical centers.

So what I am saying is that we are opposed to a large-scale single central data system and I guess that is all I am willing to say. I do not want to deal with particular programs because I don't know enough about them.

MS. GROMMERS: Senor Anglero, if I could help you...
were you thinking of having one, why the data could not be
brought centrally and not to have them all locally in --

MR. ANGLERO: This is the data, all your data would
be collected and to have them considered any place at a cen­
tral level, in Baltimore or Fredericksburg.

MR. SHISKIN: Yes.

MS. GROMMERS: We are wondering what the advantage
would be in OMB, what they would see in this.

MR. SHISKIN: Madam Chairman, I am reluctant to
answer questions on particular programs. I don't know. I
would have to study a certain program.

I could only give you a principle, as a principle
opposed to bringing together large amounts of individual data.

MS. GROMMERS: We could perhaps refine that for
you and draw that out at another time.

Mr. Impara.

MR. IMPARA: Very briefly, to follow up on Ms. Cox's
question and Mr. Davey's question, and let me give it in terms
of an example, we heard Monday from a division of the National
Institutes of Health, Safety and Health, and they are collect­
ing data implementing an act for the Department of the Interior
relative to certain mine safety. It is conceivable that they
would provide certain data to the Department of the Interior.

As I understand it, they data that they are collect­
ing on medical histories is confidential under the rule of the
Information Act under the personal information exclusion.

MR. SHISKIN: It is confidential.

MR. IMPARA: Its confidentiality is maintained because of the exclusion of medical information in the Freedom of Information Act.

I guess my question is: Does the exclusion, if they qualify for this exclusion under the Freedom of Information Act as to making this information public, does that exclusion go with the data or does it go with the agency responsible for collecting the data?

MR. SHISKIN: Gee, I don't know the answer to that. Do you, Joe?

MR. WAKSBERG: I don't know.

MR. IMPARA: Another example, if the Bureau of Census data were to, under some circumstances, provide information to another agency, whether the other agency had the same kind of legal framework for confidentiality as the Bureau of Census does, is the agency under restriction?

MS. COX: Or the individuals.

MR. IMPARA: Or the individuals or the --

MS. COX: Company.

MR. IMPARA: Are the data confidential regardless of where they are housed or by whom, if under their original collection they are deemed confidential?

MR. SHISKIN: I think it is the law that governs it
not the data, because if you have confidentiality -- the Census have a confidentiality law, and now, under the 1970 census, they collected certain data about housing and individual characteristics, and the decision was made that if it is appropriate to collect those data for the census, it is the law which gives those data a confidentiality.

MR. WAKSBERG: Maybe an example of that or some kind of application might help on that.

Occasionally in some of our programs, we feel it is useful to have people in other agencies look at it as, maybe, a joint program. Maybe they have some expertise that we want them to look at it for.

The way this is done is to bring the people from the agency and swear them in as employees of the Census Bureau, as special agents so that they can be bound by the law which says that the Census Bureau -- they are bound by the same law as we are, and if they reveal that information, they are subject to the same jail penalties as any other Census Bureau employee.

MR. IMPARA: If they fail to take that caution.

MR. WAKSBERG: They are breaking the law.

MR. IMPARA: Okay. Assume that there is some oversight where your law wasn't so straight. Let us translate it to some agencies, some HEW agencies and they either brought someone in or took their data to someone else and they perused the data or held on to the data for some period of time. Does
the law that covered the collection of data go with the data to the other agency, or does the law only cover the data while in these collecting agencies?

MR. WAKSBERG: I suppose you would have to look at each one separately. The census law says no employee of the Census Bureau -- it doesn't refer to the data. It says, no employee of the Census Bureau shall reveal any of this or permit any of this to be published in any form, and it relates to penalties to employees of the Census Bureau.

MS. GROMMERS: Mr. Martin.

MR. MARTIN: I think I can clarify the point.

The Publication Information Act mandates the disclosure of information except in several specified cases where there is a discretionary right not to disclose, so the exemption applies to the character of the information.

If an agency collected information which it had discretion not to make public under the Freedom of Public Information Act and transferred that data to another agency, that agency vis-a-vis the Public Information Act would have the same discretion not to disclose it.

If the transferring agencies imposed on the receiving agency an obligation as a condition of the term of transfer to exercise the discretion in the same manner, then the exception, in effect, would follow the data. But unless it did that, it is conceivable that the receiving agency could, if it chose
under whatever pressures to, exercise its discretion not to
make it public differently.

MR. IMPARA: Thank you.

MR. SIEMILLER: Or to make it public.

MR. MARTIN: Yes.

MS. GROMMERS: Professor Allen.

MR. ALLEN: You have indicated the usefulness of
the administrative use of data and the transfer of some longer
limit conditions grown from one agency to another and there
has been some discussion of the confidentiality implications
of doing that, and I would like to make it a little more an
open-ended question to what extent the confidentiality con­
siderations are paramount to the extent that you don't do that
even more. That is, what are the implications for privacy
and confidentiality that you are aware of that limits your de­
cision to do that even more than is already done?

MR. SHISKIN: Well, my view on that is as follows.
I think now, in here, as I kept saying, we want your remarks,
your advice.

You asked me a question so I will answer it. My
view is that respondents object to the use of administrative
data for other administrative or regulatory uses. That is a
principle we sort of observe.

That is, if data are collected for one industry
purpose or like taxes, we think we would not agree to their
use for another administrative purpose or for regulatory purposes. But we would support their use for statistical purposes under conditions that are of confidentiality.

So I would say that almost everywhere we see administrative data available that could be used for statistical purposes where the data are published as statistical totals, et cetera, et cetera, we could encourage that; Medicare records, school enrollment information. There is a child care operation. We would like to get at that so we would encourage that for statistical purposes. We would oppose it for regulatory or other administrative purposes.

Is that responsive to your question?

MR. ALLEN: Yes, I guess. It says for statistical purposes. There are no implications for confidentiality as you perceive it, though?

MR. SHISKIN: Well, I have to keep saying that when the data are transferred in such a way, that their confidentiality is guaranteed. Now, I must say that I am troubled by Dr. Cox's response about not informing the respondents.

MS. COX: Plus the fact that when you begin to link data, you reveal more and you are going to identify individuals

MR. SHISKIN: No. How long will this committee be in existence?

MS. GROMMERS: Our charter at the moment extends through June 31. May I ask why you were wondering?
MR. SHISKIN: I would hope that we could meet again, frankly, because this is a great opportunity for me, and at the next meeting we would be discussing in somewhat greater depths when there are other people here some of the questions you asked.

I think it is a very important question from Dr. Cox, just a question about practicality; what should we do? Write letters to 2.2 million respondents?

MR. WAKSBERG: How about the 72 million families on the 1040s?

MR. SHISKIN: Yes. What is our obligation? Do we write them? Is the way we are doing it okay? Do we go to the business community and talk to their representatives and tell them this is a big problem and we'd like to discuss it?

Also, Madam Chairman, I really hope we can get together before you are finished and you can sort of respond to these ideas and we can get your reaction. I would like to know what your reaction is on this issue that Joe and I raised.

Is a probability sample of addresses confidential? Or should we try to get the director of the census to transfer such a probability sample of addresses, let's say, from Census to National Center for Health Statistics? We would like your reaction to these questions.

Is our program of maximizing the use of administrator records not only for business returns, which we are doing...
on a very large scale, but hopefully as a proxy for mid-decade census? Is this a good idea?

So we would like your reaction.

MS. GROMMERS: Dr. Shiskin, we are very grateful for the opportunity to do this. As we are interviewing various committees, we are coming to some conclusions about this.

But based on some very interesting information that we are covering and uncovering as we are interviewing a large number of different kinds of agencies with the same kinds of questions, we may very well be able to have some actual data to back up what we might suggest to you.

MS. COX: We are not quite done.

MR. SHISKIN: You will eventually have the report, I presume?

MS. GROMMERS: Well, we hope we will interact with you long before that, knowing that that is going to be so long, but we would like to talk to you sooner.

May I suggest that we stand up and stretch here in the room for five minutes, and I will call you back to order. If you could, Dr. Waksberg, we would like to have you stay, if you could, and then we will go on to the other presentations.

(Brief recess.)

MS. GROMMERS: This is off the record.

(Discussion off the record.)

MS. GROMMERS: We apparently have been generating
some enthusiasm here for committee interaction.

May we do this like a computer since we are talking about automated data systems, and may I ask each of you in turn to make an eight to ten minute first pass over on what it is that you want to present to us here. Then we will get questions from everybody which may bring out details. Those that don't get brought out, we will make a second pass at.

MS. COX: Can we have all four and then questions?

MS. GROMMERS: Yes. First, we would like to have all five. We are just going to start very briefly with Mr. Waksberg who didn't get a chance to finish the other part of what he was saying. So that is going to be five minutes, seven minutes for the first half.

MR. WAKSBFRG: I should talk quickly.

Let me just make a few comments about the use of automation, record linkage, issues of that sort in the Census Bureau.

Every ten years when we take a population housing census, we obviously get a list of virtually everyone in the United States and we have these roughly two hundred million people on file, and I guess there is a naive notion that these people are filed to the extent that if anyone -- or if we want to collate information for these people with lots of other persons, lots of other information, then it is just a matter of going and finding the individual, finding the matching in-
formation from some other kind of record, collating the two
and producing whatever kind of statistics that can be done.

Well, it turns out that as a practical issue, al-
though this would be possible, which you wouldn't if one had
an infinite amount of money, but with the Government budgets
being what they are, even with hundreds of millions of dollars,
this almost impractical.

The only practical way of bringing data together,
large-scale sets of data together from various sources is if
there are some reasonably unique numbering systems whether it
is social security number or some other numbering systems,
under almost any other circumstances. The only things that
can be done are relatively small-scale jobs, things with may-
be a couple thousand people, ten thousand, two thousand, five
thousand.

We have done sample studies where we have tried to
bring bits of information together of various types but this
is just not feasible on a large scale unless you get involved
with computer matching up ratios in which case you need iden-
tical identification first. Well, there was pressure, I might
say. There was pressure --

MS. GROMMERS: Excuse me. May we just challenge
you on that. We don't believe you do need them. Could you
just say why you need identical ones and not a program that
will link?
MR. WAKSBERG: Well, by identical, if one is translatable into the other, then as far as -- then they can be considered identical.

MS. COX: If you want.
MR. WAKSBERG: As a result, where we do not have these unique identifiers, we tend to -- well, the only linkage jobs that I can recall in the census of this type are those that are done on relatively small scales to investigate particular statistical matters.

We have compared some information from Medicare records with the census to measure coverage of the older persons of the United States, to measure age reporting but these are based on the samples of a few thousand cases where we actually look and try to compare names and addresses.

The large scale jobs to be practical require numbers, and in the census, we just don't have them.

We made a decision before the 1970 census that we would not ask for social security numbers which is at present really the only universal method for doing this in the United States.

We did not ask for that because our feeling was that the kinds of uses we could visualize where we would want to link large scale records of census to other things just weren't great enough to warrant the kind of problems, public relations, problems of ethics and morality of getting social security numbers and making this available.

In fact, if you look at what we put on tape, on our magnetic tape in the population census, for example, not only don't we have social security numbers but we don't have
names, either.

From an automated basis, it would be impossible to do anything with our computer tapes.

Now, this does not hold true in the case of some of our economic results for information, if a company is so unique that in order to be able to deal with it, to be able to produce statistics, that you do need information on names. But in our population, in our demographic information where we get into data on persons, on households, we do not put any kind of identifiers of this sort on tape.

Now, we do use information from other agencies for various special purposes and then we mentioned a few of those cause some of the kinds of relations that are kind of various and that Dr. Cox related to as to notifying people of information, and there are some troublesome issues.

Let me mention one piece of work that we are doing right now. There are many pressures on the government as a whole, government statistical system to provide updated population counts for each city, each county in the United States.

Billions of dollars are transferred from the federal government to localities from the states to localities, much of it being on the basis of population counts. In the present system, these are gotten only once a year.

Proposals had been made for a mid-decade census
to update that, and as Mr. Shiskin mentioned earlier, the
costs of those things are so large that they seem inadvisable.

So we have been examining other ways of getting
reasonably good recordings of population counts, and the one
that appears most promising is as follows.

To start up with a simple technique, starting off
with Washington, Montgomery County, we start off with the
1967 figure for population, and you add to that information
that has been tabulated from birth records, from vital statist-
ics -- and these are not individual reports but simply
the number of births in this city -- you subtract the number
of deaths and this is accounting for everything except interim
migration of people leaving the cities, moving some place and
then coming back.

So we have been exploring the possibility of using
IRS data to give us estimates of movements. And the method
of using IRS that appears most promising is to take two
periods of time, let us say that we suppose that we start
off with 1970 IRS returns and also take 1972 and get the
full set of returns; this does not include the income data
but simply the fact that people who have filed returns, claim-
ing four exemptions, let us say, which indicates the number
of persons in the household who have filed a return at such
and such an address, well, we collate the returns for the
two years and the collation is completely mechanical and
based on social security numbers.

This is the only way it is practical.

At the point in collation, you look for people who have changed addresses during the two periods and you see to what extent those addresses reflect movement, let us say, from Washington out of Washington or from outside of Washington to inside Washington, if you wanted to do that.

It turns out that this technique, at present, for examination in the case is that this is a very encouraging technique and may provide us with much better estimates for the population at any point in time.

And it may enable us to actually provide annually updating of the population figures with a reasonably good reliability.

But to do this requires using 70 million records each year.

The advantages are the providing of more accurate figures for purposes which have a very tangible and definite use. In effect, the better distribution of billions of dollars in funds, the more equitable distribution.

The only disadvantage is that we are using IRS data for a somewhat different purpose than it was collected.

Now, the information that we get from IRS, we hold it as confidential under the same kind of rules, as we hold any other kind of data. The notion of feeling we have
to notify all 70 million households of the fact that we are doing this is sort of, my personal feeling, sort of a sobering thought.

And I guess my reaction is I see no reason why this couldn't be put in the general distribution in terms of press releases, information and publications and so on, and I would like to propose this for some selected uses for the committee to consider this as an alternative of these general kinds of notifications, rather than specific notifications on the household by household basis.

MS. GROMMERS: Mr. Waksberg, I am afraid it is 7 minutes now. Would you like one or two closing remarks? That would finish that first pass that we could take.

MR. WAKSBERG: Well, let me just close my remarks by mentioning other kinds of uses.

The more common use that we are making of anything that can be considered data linkage is in our economic statistics. Mr. Shiskin referred to that earlier, where an effective mailing list for many of our economic studies are based on lists, either Internal Revenue Service lists or social security lists.

There are some occasional other sources that come in but these are the main ones.

About the only information that is used there is the name, the address, the kind of business it is and the
measure of the level of activity of the company. These tend
to be sort of the major kinds of uses of data from other
records that we have.

MS. GROMMERS: Thank you very much.

I think we will just go for our second speaker.

Mr. Schor.

MR. SCHOR: I will try to --

MS. GROMMERS: Will you introduce yourself just
very briefly, first.

MR. SCHOR: I am Sigmund Schor, director of the
National Center for Social Statistics. This center is the
statistical arm of the Social and Rehabilitation Service and
as such, its program is a reflection of a response to the
various program needs of the Social and Rehabilitation
Service.

Just to give you a quickie half-minute over-
view, the Social and Rehabilitation Service is responsible
for the welfare program in the United States on Medicaid,
program of social services, vocational rehabilitation ser-
VICES and the other program which is the juvenile delinquent
program, the program of aging, and, last but by no means
least, the Cuban Refugee program.

So you can see this is a varied program and re-
quires quite a bit of statistics.

Now, we collect our data on the basis of the same
legislation; our authorization comes from the legislation which authorizes the existence, the establishment and the existence of the Social and Rehabilitation Service, so that the Secretary may decree, he may collect any kinds of information he so wishes for the proper administration of the program.

And in determining what is a good statistical program in terms of what are the needs, we do try to the extent possible to communicate with the states on the various uses of our statistics which run from the Congress, of course, the Office of Management and Budget, and various other parts of government, not to mention of course all the other sister agencies.

The data we collect are about people, recipients of welfare people who have been rehabilitated. The source of our data are the state agencies themselves, and the kinds of data we collect are primarily operating data, merely, how many? what kind? what do you do for them? what characteristics? what services have they received? and this type of thing.

Now, I am trying to cut this down to save time here.

We receive our data primarily in three ways. One is we collect data in some brief form from these state agencies. Incidentally, state agencies may be any kind of
agency that has responsibility at the state level for any
of our programs. It might be a health department, department
of human resources, of vocational rehabilitation agency,
what have you -- quite a variety of agencies we deal with,
which is one of our very many problems of course in collectin
data.

But one way of collecting it primarily is to
collect from the state a summary at the state level, leaving
it to the state to worry about the geography below the
state level.

We collect state data in a prescribed form which
are actually statistical tables.

How the state produces this is the state's affair
unfortunately, and if you keep in mind that approximately
half the states in the United States have a county welfare
program, we are dealing with quite a number of reporting
agencies.

In any case, we get these data in summary form
and I will just pass this one by and say I don't even see
any problem in that area about disclosure or confidentiality.

We are doing it with a very large area, essential
the state. As a matter of fact, the only exception we make
to that is that we do get some limited data, number of recipi­
ents I believe, and expenditures at the county level.

But beyond that, these are state tables. I don't
see any problem in disclosure, confidentiality in our area.

Now, forgive me. I am trying to breeze through this.

MS. GROMMERS: We appreciate this.

MR. SCHOR: Another way in which we collect data is, of course, the survey technique where we go out and we design a sample and we send it out to the states and we ask the states to complete our questionnaires about a survey of recipients.

Now, it is a sample survey, and for example, if we do a survey of the program called Aid to Family Dependent Children, we would probably take a one percent sample, roughly, and deal with about 25,000 cases which might cover some 75,000 to 100,000 people.

Here, too, we make very gross tabulations at the national level, not very finely detailed. Sometimes, we never have time to do this. Other resources could do this, but they are state, national tabulations, and we provide state tabulations for only a few with large enough to provide reasonably good state estimates.

I hope you can hear me back there.

And as I would say, here, too, I do not believe we have any kind of a disclosure problem because the data are, of course, a sample. They are for large geographic areas.
I don't see any problem in getting -- wrong data getting into the wrong hands.

When we tape these data and put them on to computer tapes, more personal identification is eliminated. We collect personal identification only for purposes to be able to follow back with the states where we have a lack of information where they didn't supply the data and we suspect the quality that they did in this and so on, but once it is on tape we wipe it all out and produce our tabulations.

I see no problem there. Maybe we can come back to where I see the problems.

The third way of collecting data where we have the vocational rehabilitation, we get not a sample but we get a complete record of every single disclosure made during the year. However, I am going to skip this one by completely because I know that Monday morning you had a two hour session with one of my staff members, Lesley Grier, who spent two hours on that session.

I think he worked that one out. I will pass that one.

Where are the problems? I see they are in Washington. I don't see any problems in terms of disclosure or confidentiality.

Now, one of the problems arises where, let us say, you have one of the smaller agencies and when an organ-
ization has its own computer set up, its own programmers, its own system and so on, it can sort of keep an eye on its data to see in whose hands the datum gets, who has access to the datum -- by "datum", I am talking about the original question which had come in and which aims to accuracy, being very, very specific about people.

However, we find that we have to use it because we don't have any of these resources and there are a lot of other places in the department that are small like this that don't have their own resources.

They are obliged to go to a central processing organization in another department called DMC, for example, in our own Department of HEW.

What you find when you send that over is the obvious; they don't have the resources either, and the next thing that comes up is a dirty word called "contractor."

It is a dirty word because we can't control this. We have no way of keeping control or a handle on it as to who has access to the data. I consider this a very major problem.

We, locally, try to make an inspection. Maybe it is a term, a funny term. We can't keep up with it. If it is local, we put our heads in and see what they are doing, lay the data all over the floor and so on.
But even so, you have it written into contracts: there are certain prescribed formulae, you will maintain confidentiality, and so on.

There is absolutely no formal audit made. There is a potential. I would not say it has happened, but I can see a very good potential for somebody, some contractor perhaps faced with financial problems using these and making up mailing lists and selling mailing lists to some poor people.

I don't see anything to stop them. But of course there is a law that says it is confidential.

The second area where I see problems is in our states. These are the suppliers of our data.

All our regulations prescribed that the state plan, under which the states operate, have a clause of confidentiality. It is very impressive, it says so. It is written in the Federal Register.

I saw on the roster where there are probably two state assemblymen, senators, state legislators, I don't doubt the ability of either one of these calling, picking up a telephone and calling the county welfare and finding out about anyone he wants to find out on, on the rolls.

Obviously it is a political program, and I am sure that this kind of thing is potentially possible.
Even when you go beyond this, the states, there are 54 jurisdictions that we deal with directly and 54 levels of sophistication and computer equipment, and how they handle them and at one extreme, you will undoubtedly find some states that have built in safeguards on data.

I am sure there a few in number.

On the other extreme, you have states that deal with manual systems and they have data on 3 by 5 cards with lines all over the place, and even there, when you have automated systems, you learn about the protection, the integrity of the data.

In many states, the agency with whom we deal, the agency which is the source of this information, and the training has to do with some other central place, which is just the situation mentioned a while ago, was to the central location and to the processing of it and they would say, "process it for me because I am required to report those data to somebody in Washington." What happens?

Again, they may be overloaded and they go to a private contractor. So I see information about people, I mean real live people, names, addresses, right on down the line, being circulated and in the hands of people where we have, or what I consider, darned good protection.

I repeat. I don't think we have very much problem here at the Washington level. We do take reasonable
care and precautions.

I am reasonably sure of this.

What happens out there in the world is the states and what entity within the state has a part to play in the manipulation of these data, and in the world of private industry I think there is a potential problem there on confidentiality and disclosure information.

MS. GROMMERS: I think that is a very beautiful presentation. At this point, I presume you are speaking about a budgetary problem with your short staff?

MR. WAKSBERG: It is probably. I don't think it is a budgetary problem. I think it is a political problem.

I would like to point out that we are taking steps to help states, to provide guidance, counsel on hardware, software, methods of processing data; in other words, of trying to bring some order of standardization into this whole thing, and once you reach some acceptable level of standardization, I would consider the next step would be to build in very specific safeguards.

How do you protect them? Are they safe? I don't know. By swearing in people who may have access to it? Maybe it takes law. Maybe it takes additional law the way Mr. Shiskin was indicating. I don't know. I think that eventually can be locked.

The other one, the contractors is a matter of --
it is a budgetary problem, obviously, if you don't have staff
where you hire people to do it for you.

There truly is no alternative. These people
should be on the government payroll.

MS. GROMMERS: I'd like to come back to that
point and I am sure the other committee members will do it
for me. Maybe we ought to go on to Mr. Carroll for the
moment.
MR. CARROLL: I am Jack Carroll, the assistant commissioner for research and statistics in the Social Security Administration and our office is the research arm for the old age survivors disabilities health programs, just as Sig mentioned that his organization is prepared for SRS, there has been an office of this type in Social Security from the beginning of the program.

Fortunate for the program, it was written into legislation and we continue to do a lot of research that you might expect may be necessary in this area, make available statistics for this. We do not collect statistics.

I think it is an important point to make, that most of the information to be used is collected in the operations portion of the Social Security Administration in doing their functions, collecting information about the wages of the people who they cover, and they do that from about five million employers and indirectly then, through the employers, get the information about the wages of something like 90 million workers each year.

What we do in OAS, we have five divisions. One of these divisions is specifically oriented toward accessing this information from the operating records and, of course, the thing that interests me most is that I am getting those for research projects in which we are interested and for general information and statistics which we feel need to be
made available to a wider unity. There are also a good many administrative uses of these statistics, and I take it that is not your major interest.

We publish a lot of this information because it is generally useful to have it available to a very broad community and the division of statistics in our office makes available information, such publications for -- well, we have an annual statistical bulletin that goes along with the Social Security bulletin where we publish a great deal of information on a monthly basis.

We also publish a number of annual reports on special subject groups; for instance, farmers and farm workers, household workers, state, local government employees, farms, subsidiaries, self-employed doctors. Lots of information with very specialized type.

We also make available to the Congress information about beneficiaries amounts made and so on, on a state and county basis, and we supply the Census with information for the county business patterns.

Just recently, we began making another use of the information to give people an idea of what the earnings distributions are in the largest SMSA's in the country for people, broken by race and sex.

As you can see then, there is a wealth of information here, and our objective is to make it available
to a broad community, society, so it can be useful because we
never could hope to type it ourselves. So we try to make
use of it in analytical studies in which we are engaged.

I will say something quickly about the fact
that we also make the information available on tape, some
parts of this information. We, from very long back, had
taken a 1% sample of our records and in recent years we have
been willing to sell that, put it into a form where identifica-
tion has been stripped off and the information is useful
for statistical purposes. We are willing to provide quite
a bit of technical assistance in order to make it really
available to people.

I hate to get away from that. That is one of
my favorite subjects, but will go on to say that we also
realize we need to have information about the whole population
at least and not those that we just happen to reach. So we
have to do a whole series of surveys. And I say "we" do them.

Actually, we design surveys but we contract with
other agencies to collect the information; usually Census, and
when we do that--John Waksberg has pointed it out for us which
I don't have to repeat--we make an arrangement that the people
are sworn in as Census agents so there is assurance that there
is the same kind of confidentiality at the Census that is
guaranteed people.

In this way, we ran a First National Survey. The
agent ran a First National Survey of the disabled, and when Medicare began, we realized we had to get information about how the Medicare program was working as quickly as possible. We have done that on a monthly sample basis, again working with the Census.

Now, who decides what is to be done? I tried to look over your questions. I didn't realize I would have to answer them in seven minutes. Actually, as we proceeded, I thought it would be more fun to ask the questions that has been asked at this seminar.

This seminar is kind of good fun, actually. I shar Julius' view on that.

The Commissioner ultimately is the man that decides what we are going to do. But just as all commissioner he takes advice from a lot of people. We depend a lot on advisory groups and usually these advisory groups have come from professional societies, from academic circles, from other research organizations and give us some feel for what they feel would be helpful.

For instance, before Medicare statistics were put together, we had the advice of very distinguished groups from outside the government.

As far as matching is concerned, I want to quickly say that we do these surveys from outside by using census, generally the census. Sometimes we want to enrich the information though by linking it up with our own information.
If, for instance on the longitudinal study on the retirement history, we can find out what the earnings of these people are, which we can do from our own records, we put that information together with the information that they have given us. And then we have more information than, as Doctor Cox has said before, maybe they realized, because I don't believe we tell them that we are going to do that.

But on the other hand, we keep all the information just as confidential as we had told them. All right.

I think it is an interesting question that was raised earlier about what to do about that. I want to mention something that many of you may know about, and that is that outsiders are forever sending social security numbers and wanting us to "give us some information" and saying, "Golly. We don't know what to give them." If people are willing to waive their rights and give permission for that, we don't have much choice. We have to give that information.

We do not encourage that. In fact, we discourage it in a way, by explaining to researchers some problems related with that and try to get them instead to give us social security numbers if they have them simply for statistical tabulation feedback to them which is much, much better a way of doing it. And from their point of view, as well, it is a better way. We try to persuade them of that.

Now, as was suggested earlier, there are from
time to time efforts to link, cooperative efforts to link other information with the census, things of those sorts. Most of those are for methodological purposes and serve a very useful purpose.

Again, as Joe was saying, it might be very difficult to think and tell everyone that we are doing this and I don't believe that we do, but take the case of their trying to find out better information about people over 65. You know, to get Medicare, to get social security, you have to prove how old you are. I mean, you really do. That is a very complicated process. And so our records about people over 65 are better than just plain survey information.

What the Census wants to know is how much better, how much different, you know. And therefore, we supply that information to them on a cooperative basis so that they can improve their methodology.

In order to get that information, incidentally, even though the government is dealing with itself, the Commissioner has to exercise his prerogative under what — where did Julius go? — what Julius said is not very tight confidentiality. I thought we had a pretty tight one.

It is true, however, and this is what Julius had in mind, of course, that under certain number of situations, if the Commissioner and Secretary wish to do so on an ad hoc basis, they can make an exception to the confidentiality
restriction and we did that in order to give the Census this information. That is an illustration of when we do it.

As you can see, I could go on and on. But I will adopt Doctor Cox's term and say "pass." Must have been Ohio.

MS. GROMMERS: Thank you very much, Mr. Carroll. We will appreciate your pass and hear from Mr. Simmons.

MR. SIMMONS: I am Walt Simmons, assistant director for National Center for Health Statistics. Now, our Center is not in the business of automated personal data systems and, indeed, we have taken quite a bit of efforts to stay out of any operational role in that field.

But, contrastingly, we do of course deal heavily with information about individual persons and individual business establishments and we are very much concerned about questions of confidentiality, invasion of privacy, Freedom of Information and all these related topics.

Our general position in these fields I think is very similar to that which you spent a good bit of time this afternoon hearing from Julius Shiskin and Joe Waksberg, that we sometimes say in our Center that we are something of a lineal descendant of the Census Bureau; at least in the handling of data in those respects.

We do make a great deal of distinction, a very sharp distinction between the use of data for statistical
purposes and the use of data where the individual unit can be recognized and possibly used for purposes of administrative uses or taxation or regulation inspection, any such kind of activity of it, we are not engaged in any of the latter kinds or types.

Now, we did have from your secretariat quite a list of questions to which we might address ourselves. I was impressed, if I may say so, with the insight and the perception of underlying issues that was behind that set of questions. I think there were about 53 of them. In the seven minutes that we have, I am not going to deal with very many of those. So I will take our Chairman's direction and simply refer mostly to things that we might have talked about if we had more time.

I will say that our Center is the principal general-purpose collecting agency in the health field in the government, and is so recognized as a part of the federal statistical system which was referred to earlier.

We collect data through a great variety of techniques and over quite a range of health topics. I think we currently recognize some 17 different general mechanisms for collecting data in such areas as the vital events field: births, deaths, marriages, divorces. We used the household interviewing. We take probability samples of population and give physical examinations to these people.
We have inventories of facilities which provide services in the health and allied fields. We have a system of sampling of hospitals and discharges from those hospitals and character of people in the hospitals.

We deal with long stay institutions, both one hundred percent and samples. We cover staff. We cover facilities. We cover the residents of such places. We have a nutrition survey.

We have several kinds of what we call record anchored surveys, following back surveys where the frame for drawing the sample is such things as the vital events certificates and we go back for additional information.

Then we have several other kinds of techniques. Now, we are the largest health collecting unit in the government but by no means the only one, not the only one even in the department.

As a matter of fact, I think budget-wise, we have about $19 million of a budget currently. I think the rest of the department has something in the neighborhood of $30 million in budget.

Our programs are distinguished especially by the fact that they are national in scope. They are continuing in character. They are general in purpose. They are baseline background kinds of data.

We have quite extensive legal authorization both
in terms of latitude and in terms of direction for topics which we should provide information. There is one other area of legislative activity which I want to mention very briefly and it came as a little bit of a surprise to me today.

This deals with the question of our -- the legal basis for our handling of confidential matters. I was a little surprised to find Julius Shiskin mentioning that only the Census Bureau had an adequate law in this respect, and we think our law is pretty strong in this respect.

We believe that it prohibits absolutely no transfer of information to anybody outside our Center without the consent of the person supplying the information. I will talk to Julius some more about this.

On the question of program determination as to who decides what we do, well, of course, in one sense, Congress and the Executive branch of government generally do this and our own organization, internally. But in particular, there are I think four points that I might mention in this connection.

There first exists a U. S. National Committee on Vital Statistics which has been appointed by the former Surgeon General and now by the Assistant Secretary for Health and Scientific Affairs which is a public committee widely representative of, generally speaking, the health of the community of the country which is advisory to all of our
activities. A second thing is a mail -- that's m-a-i-l -- panel of 150 advisers which we try to keep informed by a series of outgoing communications from our office of what events are taking place and what we expect we may be doing in the future and inviting comments from these people and suggestions and recommendations.

We get a very heavy flow back from our 150 panel members and we are pleased with this technique. It is one of the most useful and valuable devices we have.

A third element is or was called a public health conference on records and statistics. It is called a conference but it is a thing that extends all the time, exists bi -- meets bi-annually and, in between meetings, is served mostly by derivative technical consultant panels which are sort of subcommittees of the conference organization.

This is mostly people by universities and by state and local personnel.

Finally, we have a formal annual internal program review which consolidates all the information that comes in from other sources, and our own organization that tries to set up a program budget each year. We use publication, printed publication as our primary method of distribution of information. But we do have a policy of making available magnetic tapes for elementary units in a form in which the elementary unit cannot be identified as an individual person
I will leave with you a little pamphlet that describes how we go about this. I think that my approximate seven minutes is about up.

There are a good many -- as I say, I was impressed by this list of topics on which we might comment. There are a good many of them on which there are things that I might like to say, and I would like to get some reaction from you. But I guess in this first round, I will have to pass over most of those, but I would close with one other kind of remark which echoes in some respects, at least, what Mr. Schor said a few moments ago.

Now, for us in the National Center for Health Statistics, I think I can say that there are a few matters that take more of the time and attention of our senior staff than these questions that are under discussion here today.

Somebody raised the question a while ago of confidentiality being paramount. Confidentiality and related matters are certainly of very significant aspect in our undertaking. There are new things happening every day.

Now, up to the present time, although it's been sometimes fun and sometimes very difficult, I think we have kept pretty well on top of this question. But our Center, as I indicated, has mostly been engaged in national surveys and has been federal and national in scope and we are now heading
into a period in which we will be a part -- in addition, a part of a cooperative federal, state, local activity in the health field. And here I have a good bit of uneasiness about our ability to maintain the same kind of standards in this field that we have in the past and the problems come in our eyes in two directions primarily: one, even among the statistical agencies, and if we restrict it just to states, we will be talking about 50 semi-sovereign jurisdictions instead of the one that we have to contend with at the moment. On the other hand, and perhaps even more severe, is the problem that at the local and state level, very often the statistical organization and the operating activity and inspection organization or regulatory body are very nearly in the same organizational setup and it gets extremely difficult to keep the wall between the statistical purposes only and the operational uses in such an environment.

I think this constitutes one of the most serious types of problem for the statistical people in this realm.

MS. GROMMERS: Thank you so much, Mr. Simmons, and thank you also for the quick pass. We will introduce to you Doctor Nisselson and then we will be able to have those questions you have all been waiting for.

MR. NISSELSON: I am Harold Nisselson, Assistant Director of Research for the National Center for Educational Statistics which is the statistical center of the Office of
Education.

What I would like to do is submit for the record some material about ourselves and a statement and just talk a little about some of the problems that we think we have and try to get your help on them, try to answer the questions that you may have.

First of all, we are probably unique in some sense because the Department of Education, as it was originally called, was founded in 1867 -- wasn't it? Yes. -- solely for the purpose, entirely for the purpose of collecting statistics and facts about education in several states, you know, the kind of language they had in those days.

After about 98 years, in 1965, this explosion of federal activity and federal concern in education, which constitutionally is a local concern, took place. And with that came the explosion on information demand and in response to outside advice, the Commissioner established the National Center for Educational Statistics in 1965.

So it really is a very new Center and things have just been going from bad to worse. It's kind of like living in a high-temp cannonball reaction; lot of heat, lot of things happening very fast. And I think we not had the time to develop tools nor the traditional tools that other fields have had, and I think that we are hurt a lot more because of that even though our intentions are good.
We started out originally with a great deal of concern particularly because of the local orientation of education, with education as an industry, if I might call it that. And it wasn't until the compensatory legislation that the federal government really got interested in things like process, what was going on, what were you doing to the kids? which created for us the kinds of problems of information about individual teachers, individual students which created the very difficult problems of confidentiality.

I might illustrate the changing attitude of people by telling you about a Ph.D. candidate at Columbia a couple of years ago who got to wondering if education is now failing children. It is not educating the children. At what point did it start failing them? There was some time when it was serving them.

So he started moving around in early records in New York State and he was able to find something like in Baltimore, Syracuse. They tested all the cases and so on. And he found that in the higher Victorian age where schools were in well-disciplined shape and kids were shot within 300 yards, they were failing the same kids.

Now, it is just that we are now getting impatient with them. We are not willing to have that failure continue. We want to serve our kids and to improve ourselves.

Well, all this period demands for a lot more
detail, information on a federal level for program insight
for really being able to describe the condition and the progres
of American education and have sophisticated terms in terms
that we know that it can help the local states so something
about it and not multiply their problems.

We collect data under the general act. We are
asking for some legislation because we think that we need
the Census confidentiality law.

At the moment, we assure people that we will try
to keep individual identifying information from any publica-
tion and we try to do things like use the face sheet which
we can tear off the identification and, generally speaking,
in cross section service, this isn't much a problem. You
don't really have to retain the identify of the individual
unit.

There is a confidentiality problem because if
you talk about a private four-year law university in New Haven,
Connecticut and which I just saw in some miscellaneous, every-
body knows you're talking about Yale. So for that reason,
Yale doesn't and never has.

We do have problems, standard procedures
established for doing analysis of our tables, doing secondary
disclosure. There are some problems there. Don't smile so,
Madam Chairman.

(Laughter.)

MR. NISSELSON: So that does hamper our ability
to serve some of our uses particularly in higher education
because, there, there's a tradition for the uses at the
institutional levels to compare yours with other institutions
who you would like to be the peer of or who consider you
their peer and to use that kind of thing for analysis.

But the real problems and toughest one of
confidentiality will be where you want to do longitudinal
studies. So, there, it is necessary to retain the identifying
information.

To try to give some meaning or more explicit
meaning to what I should say, what Julius was saying about
tough confidentiality provisions, I don't care whatever the
provisions are, whatever the law is, whatever the penalty is,
you really cannot guaranty confidentiality.

The only way you can guaranty confidentiality
is by not having identification there. It is like game
theory. If you want to fool your opponent about your strategy,
why, you use a random so you don't know it yourself so you
can't tip your opponent. So we are trying to approximate that.

We try to keep individual identification off the
document or off the computer tape that has the individual
information. We have one translator between going from a
name to the individual and that is on the lock and key and,
you know, we try to keep monitoring that.

I think we do have some problems of the kind that
Sig was talking about. But they are not with our contractors. They are with our own internal people. If you know the DMC, if you know HEW's computer system, you can get anything you want. You just have to know the right numbers to call for, that's all.

We think the department itself is very conscious about this. The Assistant Secretary for administration management is now in the process with the help of people, I guess with your advice, too -- thank God -- is in the process of revising the manual which is going to implement things.

We look to that to help us. We look for strong endorsement from the Committee with encouragement of OMB to get ourselves legislation that will hopefully let us shake a finger at people and threaten them. But we think we have to try the most we can to just keep the information off, to try to keep identifying information off if that means we are not so efficient. We have already given up efficiency.

The greatest efficiency would be to one response, one sample for everything. But we have decided that was too much burden. So we are already hung up on some kind of price and we think that confidentiality, protection of the rights of the individual is very important and it is worth spending money for and it just goes everywhere.

When you think of the kids in school who get all
kinds of things like, "You're educable, mentally retarded. 
You're not educable. You're just mentally retarded." Some 
of this information may have been the result of professional 
advice and there is no way to protect it if a Congressman 
comes here.

That's what happened here. A congressional 
committee got some data from the Washington School System 
and laid it out on the Congress Record. There were names of 
kids here with all those derogatory data, information about 
them which they had no opportunity to challenge or to 
attack.

This is an area I think we are getting into 
which we probably do not have any answers on yet. But we 
want to try to develop some and that is information which 
state and local agencies collect on our account. They 
collect it because we ask for it.

We have depended, I think, on the tradition of 
the ethical profession among school people in order that 
they are protecting their kids and so on, and they don't want 
the records and so on. Sometimes, I think the only people 
I don't want to see the records are the parents, speaking 
as a parent. It seems like people can find out things about 
my kids. I can't.

But anyway, we think this is an open area which 
would be a working committee to look at and we would like the
benefit of their advice about it.

I hope I haven't caused you heart failure, Dave.

Thank you.

MS. GROMMERS: To the contrary. I'm sure his heart is in very good condition.

I want to thank you first of all for your very fine presentation and we are of one great disadvantage in that we are not able to spend much, much more time on all of these. We want to let you know that we hope that this is just a preliminary and that as we are learning more, we will have more questions to be asking.

We may have more data on which to base some kind of insights for you and we hope that you will be back, that you will be kind enough to come back to talk with us.

I think what we will do is start with Senor Anglero. Do you have a question for any one of the gentlemen in particular?

MR. ANGLERO: For all of them.

MS. GROMMERS: For all of them.

MR. ANGLERO: Thank you very much.

Well, I want to try to just make one question. I will say on your statement on possibility of guarantying confidentiality, I like it in some way.

I just want to ask what is the linkage in this case
of all the HEW centers of statistics, of the Office of the 
Assistant Secretary of planning and evaluation?

MR. SCHOR: What is the relationship?

MR. ANGLERO: The linkage to all of HEW centers, 
as such, with the Secretary of planning and evaluation?

MR. NISSELSON: Functionally, we have rela-
relationships where they have overview of evaluation in the Office 
of Education and we have participated with them and with the 
Director of educational evaluation, on studies of education 
data collection that I have been consulting for them, and 
have even done some operations for them. Is that the kind 
of thing you have in mind?

MR. SCHOR: I think you might consider them as 
users of our data. They need data for the evaluation and 
come to the Center.

MR. ANGLERO: Do you find out that this data is 
used in terms of their responsibilities, long-range planning 
and all this?

MR. SCHOR: Of course they are one of the many 
users of it. Congress expenditures budget, et cetera.

MR. CARROLL: I think that probably all of us 
sort of skipped what we figured that lots and lots of people 
had already told you.

Every agency like ours has a lot of different 
complaints. We have requests from the Congress. We have
requests from the Secretary's Office, particularly this
planning group. We have requests from the Commissioner
himself, other parts of the agency and so on.

We just assume, you see, that since they know
we have the information, when we have a problem we will try
to get us an ultimate mechanical question. In many cases,
unless you have had sense enough five years in advance to
know what is being asked, you are not going to be very helpful.

That is why it is extremely important to have
research organizations where the people come from sufficient-
ly wide spectrums of the professions that are watching what
is going on and to be able to anticipate things.

The kind of research in modern society that we
are talking about takes a lot of time. There is a big, long
lag time, and so part of our function is to work carefully
with these people who are trying to answer questions. What
will the department be doing in the next few years? And who
are responding to congressional initiative?

We work closely with them not just on what they
want right now, but what we think they will be wanting,
you know, in a few years.

For instance, it would have been absolutely no
use at all two years ago to try to help the people who were
interested in this disability if we hadn't put the disability
in the field survey in the year of 1966, you know. We would
not have any information.

MS. GROMMERS: Does that answer your question, or would you like to draw that out a little bit more?

MR. ANGLERO: Let me say I would not, at this moment. Maybe we can talk about this at another opportunity. I would like to see a better explanation in terms of relationships between them and the whole process of decision making and planning, if that is okay. But it would seem better not to pursue on this question.

MS. GROMMERS: One point you were really asking is when the data all get together with the bureau of planning, does it in fact get together all at one time?

MR. ANGLERO: Well, if there is a system established to do that.

MR. CARROLL: Yes, there definitely is. The Secretary's Office has a set of program memoranda. In fact, I am not at a meeting this afternoon because I agreed to come here and where I was supposed to be looking at what our response would be to the program memoranda on income maintenance which the departments put together over the last few months and we have seen several drafts on that. We have commented on that. We have talked to people who put it together. They have requested reams of information on it for us and we have had to make whole series of estimations and new calculations which we had not anticipated at all.
Furthermore, as you may know, the Office of Management and Budget has told all the agencies what they will have to cut and so on and so forth. We have been in the process of working out what parts of the program could be changed if you were going to try to meet specific percentage point drops in outlays. And we have had to calculate what the cost of those would be: how many people would be involved, what it might accomplish and so on. And that is the kind of information we get all the time in a routine manner.

MR. ANGLERO: Well, just to stretch the question, why is it then, if I get the correct feeling, that there are between -- you have got different setups, different ways with dealing with information. For example, Mr. Schor says there is no problem with confidentiality and Mr. Shiskin says, "Well, I have no -- the best way is not to get information."

MR. CARROLL: Different programs.

MR. ANGLERO: Different centers informative of criteria and the way to look at it.

MR. SCHOR: It has been said that the United States Department of HEW is the holding company and, effectively, it consists of a series of municipalities.

MR. NISSELSON: It may be that the department has finally decided not to cross that --

MR. ANGLERO: Just a question for --
MR. NISSELSON: You have the evidence that this is now going to happen, as I understand it.

MR. CARROLL: Well, I think that I'd make a comment on that, that this is the evidence that people realize that this is the problem. But the solution is a long ways off if you are talking about how you are going to talk about national statistics and take statistics from not only -- I mean, talk about 54 units. He's talking about hundreds and hundreds of units that report when they feel like it. That's the real problem.

When they feel like it, they report to him. If they don't feel like it, he has no way to make them report. How are you going to get those together?

MR. NISSELSON: We think there is a way to do it but it isn't by melding.

MS. GROMMERS: Please go on.

MR. NISSELSON: We see the same thing happening where you have a great deal of local autonomy and a great deal of inability to communicate and it is hard to know what people are talking about at different levels. They talk about programs.

Well, everybody's got their own definition of programs.

The Office of Education has a long cooperative tradition of putting out handbooks which are presumably
standard data elements and should provide means of communication. It is an honorific assignment to be asked to be on a handbook committee. And Al Lichtenberger who talked to you is probably the best man in the Department of HEW and more people know his name than Secretary Richardson, believe me. David Martin, really, if you want to get along with education, you stay close to Al Lichtenberger.

The definition of a part-time pupil, in our handbook, is a pupil who goes to school less than full-time as determined by the state.

(Laughter.)

MR. NISSELMAN: I mean, the intellectual content is hard to find. Essentially, we have attempted to keep two classes of accounts: part- and full-time. Maybe it serves the purpose of getting the full-time pupil in the end.

We think we have to get the people on the same kind of state, local, federal system that Walt was talking about, which they are doing in a different way in health but are trying to approach the same kind of thing.

We think we have to get people together but they are running out of money. If revenue sharing means anything, it means they can't pass the law anymore. Now, U. S. Revenue can have four people who are filling out forms on Ford Motor Company. Now, they only have Ford Motor's federal revenue and
when Ford's revenue -- when they find out something's wrong, they'll say, here, you close the sale and pass it along; the state analogue can't -- the state analogue privileges get their privilege by educating kids. There isn't anybody in our level doing anything for educating them and the state department isn't. The state department isn't. It is all at the local level and if they can do it with the grass roots level at my state, that's great. Nobody cares about what information or data they have.

If we want to find out, we have to create some systems. We have got to go to the federal government. It has got to pay its share of the pay initiative, of getting people in and agreeing on what is some kind of core data that we need to know at all levels and we think that's the way to do it. You're not going to get it by mashing things together. You're going to get it by making the systems work together and getting the resources that are required, and I think the people at the local level are responsible. They don't give you things that they know are wrong and I have not yet to find people in education who don't really want to do something for the kids. They don't like parents nor accountants but they do like kids and they want to help them but they will give you the facts if you will give them a chance.

Excuse me.

MS. GROMMERS: Do you have a --
MR. NISSELSON: We call that program CCD-7, the Common Core of Data for the '70's. Very unimaginative.

MS. GROMMERS: Do you have a description of this in your provision for privacy protection of individuals in the --

MR. NISSELSON: Well, it has some intentions about it. We have asked for legislation for confidentiality and we hope to get it with the help of the department.

MS. GROMMERS: Could we have copies of whatever documents you have up there?

MR. NISSELSON: Yes. Right. It may be a little more informative and less purposeless.

MS. GROMMERS: Mr. Siemiller.

MR. SIEMILLER: I'll pass. It's getting late.

We'll have him back.

MS. GROMMERS: Mr. DeWeese.

MR. DE WESSE: I pass.

MS. NOREEN: I pass.

MS. GROMMERS: Mr. Gentile.

MR. GENTILE: At the risk of alienating everybody in the room, I will.

MS. GROMMERS: You certainly don't have to pass. You're going to be here for another 20 minutes.

MR. SIEMILLER: You must be kidding. You may be.

MR. GENTILE: A few statements were made. One is
the statistical centers can have confidentiality by
eliminating the only trace of identification which I agreed
to. If we eliminated the identity of the person in the file,
we don't have this risk. Assuming also that we took some
precautions on small statistical samples that revealed the
same thing, what I am more concerned about is not so much
about what goes on in the statistical centers that you have
run, as much as I am about -- what is it? -- twelve or more
billion dollars that goes out to the state in Mr. Schor's area
of social rehabilitation services --

MR. SCHOR: More than that.

MR. GENTILE: And I am concerned about the lack
of enforcement of confidentiality in the states.

You mentioned that there are SRS approved plans
that have very strong confidentiality statements in there,
but that they are not implemented and I think perhaps audit
procedures ought to be established. I realize this requires
budgets but operations of audit are certainly in order if you
are going to accept responsibility for the programs that
you fund.

And I am also concerned about the many things
that I feel can be done that we have not done and I am not
saying you gentlemen, I am saying we in this room, we in this
whole nation. There are many administrative things that we
can do. I do not believe that privacy or good administration
can or necessarily should be legislated, setting up require-
ments for the operations of data centers, establishing
custodial responsibilities, all the things on our check list.
Many of them can be done within the current framework without
any change in legislation.

I think there are very, very few that cannot
be accomplished without new legislation and perhaps one
that comes to mind immediately is something Mr. Shiskin
brought up about the subpoena, needing legislation to exempt
files from subpoena.

So I bring this to your attention because where
you ask us, what would we recommend that you do? We are
similarly asking you as administrators, what do you do or
what would you do within your current framework?

Now, at the completion of this Committee's work,
I would hope that we would have some guidelines, some sample
regulations or quality assurances and systems development,
procedures, codes of ethics, whatever that we will present
to you in the hope that it would get on down to states and
local governments. And, incidentally, I am from the state
so I am not talking against anybody but myself and colleagues.

MR. SCHOR: Is there any truth of what I suspect
that goes on at the state level?

MR. GENTILE: Well, you have said a lot.

MR. SCHOR: Concerning filing of confidentiality
disclosures?

MR. GENTILE: Strangely enough, I am not aware of a single case of violation of an individual's privacy in a state, and this would lead me to another point.

You mentioned that we have to be very careful of the potential problems that centralized data operation creates. I might add that they sometimes solve some problems, too, and just because we might have 20 or 30 agencies operating in the same computer center doesn't necessarily mean that we have less privacy or less protection or less security.

If we administer properly in a central data center, we would have better security than if we had it decentralized.

If we administered better in a decentralized unit, we would have better than in the centralized. So again, I bring up the point that administration plays the key role in this and that we cannot wait for legislation.

And to get back to Mr. Shiskin's comments, my understanding from reading the Federal Register some while back concerning the new role of the Office of Management and Budget was that the Office of Management and Budget would get precisely into these things, into management information systems and the kinds of guidance that must come from somewhere, and I don't think it is going to come from the legislature or the Congress. It's got to come from administrators
and I say this not as an indictment to you gentlemen but to all of us people in this country.

MR. SCHOR: It must be understood, too, that we are talking, besides legislation, of the necessary resources to carry out orders such as you suggested. It takes money. It takes time.

MR. NISSELSON: There's a lot of this.

MR. GENTILE: We do live in an economic world. We can't do everything that ought to be done, so we have to choose and set priorities and I would think that this being one of the key elements or paramount concerns, we should establish a high priority for it.

MR. SCHOR: All right.

MS. GROMMERS: Did anyone else like to come back to some questions? Would you?

MR. ANGLERO: Well, yes. I found out through the Chairman yesterday, or somebody commenting on something, I find out that there is some kind of difference when we get the people from the Office of Education yesterday that came. I figured out that there is a kind of approach that is very much different for that kind of approach than the one I know in professional welfare and this. And it looks to me, yesterday, it looks to me confirmed today that there was an effort not to get involved too much in state and local affairs in terms of education, trying to establish some kind
of common generals and language source to communicate. But in the other programs, those which I know, it's different, completely different. So it's a process with one agency.

I'm just looking here at the transitional chart of the administration of welfare. It looks to me somehow strange how it happens. That's why I make the question.

Why do we have different approaches in terms of or different kinds of structural centers? I was asking the bureau of budget -- management and budget. They do have total responsibility. They do have in budgeting and in management.

MR. GENTILE: I think -- I think I followed your point along the same line. To intervene in some way or advise, what is your advisibility in this aspect?

MR. CARROLL: I'd like to make a comment because I think you thought the answer was nonresponsive. What we were trying to say earlier when you decided we'd come back later was that the programs that Sig is talking about are not national programs.

They are programs that if you pick one state, you look at the situation. You go to the next state and it's different. You go to the next state, it's different again.

And he has to keep track of all that, all that variety. But in the program that I'm talking about, it's a national program and, therefore, we don't have some of his
troubles. I think what I would say is, suppose HRl passes, then you fellows will find out how difficult it is. I have said that in the beginning.

If the Social Security Administration has to pick up part of the, let's say, aged, disabled, blind on a part basis, we give them a retention. But they also retain in some states, program assistants, supplements plus having the services then, you know. We already are trying to plan what kind of statistics would we -- will we need, because if we don't plan what kind of statistics we will need, there's no way in the world we will be able to keep track if legislation passes.

So we have been busy trying to figure that out. But it is much more complicated than what we have been doing.

Now, our office used to do that because you know that HEW didn't have welfare and the social security program split before, and early in 1963 they were together. I wasn't there, but they were there, and they have a lot of experience in dealing with that.

But when they made the separation of welfare and the social security programs, broke them apart, the people had to keep up with all these variations in all the states. They had a mammoth problem, plus no teeth.

You know, are you going to tell the state, "Look, you either send in the statistics or we're not going to give
you the money to feed the children'? They're not going to
do that.

MR. SCHOR: But there is legislation. They can
be held out of compliance.

MR. CARROLL: Of course they can, but it means
nothing and so --

MR. NISSELSON: You don't really want to -- you
don't want to starve kids.

MR. CARROLL: I don't know about that.

MR. NISSELSON: Your kids.

MR. CARROLL: What they are saying is a question
that --

MS. GROMMERS: Excuse me, gentlemen. We're trying
to get you all down for the record. We have one staff
question that contains an essential piece of information
for us.

MR. CARROLL: A question I'd like to ask of
Mr. Waksberg and I think the best way to ask it is make a
statement and invite him to make a statement and correct my
statement and perhaps try to answer my question.

In connection with the 1970 census, the Census
Bureau, it is my understanding, developed a system for coding
geographic, small geographic areas down to the block level.
This system is alleged in the legislature to have some
important uses present among them. It gives the government
agencies the ability to reconstruct since they put pieces of
census information in about groups of people, geographically
defined together in ways that correspond to the
jurisdictions of their programs, and this applies to states
and localities as opposed to the previous system where one
took census tract data, and then tried to -- and then often
the census tracts often did not conform to the boundaries of
the program.

I will give you an opportunity to correct that.

My question is: In considering the uses of this
gecoding system and as a computer matching technology that's
attached to it, has any systematic thought been given by anyone
in the Census Bureau or elsewhere, to your knowledge, of the
uses that could be made of matching by geographic area, data
on groups of people down to a certain level that would provide
an acceptable substitute for the uses that are now thought to
require matching on some kind of individual-like identifier?

MR. WAKSBERG: Well, the answer is yes; a lot
of thought has been given.

MR. CARROLL: And, if so, could you tell us what
they are?

MR. WAKSBERG: Well, let me just mention a few
additional details. The geocoding system we developed
originally for the census. But obviously, when once we had
a tool -- there's nothing confidential about this I might say --
this geocoding system is simply a method of translating addresses to a piece of geography, geography being an individual block. It might be a tract. It might be a city. But it is an automated system so that if you have any agency -- any agency has a set of records with addresses on it, they can automatically on the computer get a geographic identifier for those.

We are making those available to other government agencies, local communities as well as private organizations essentially for two purposes. The purpose you mentioned was one of them; one purpose is because a lot of -- in particular, local planning outfits find it useful to get geographic tabulations of their own administrative records, building permits, for example, building permit information to give information on where construction is going on in the metropolitan area, health records, crime statistics and this is a tool.

Now, in addition, this became apparent with the other use, the one you mentioned that can be brought into play, that it is possible to collate other information, let's just say health statistics or birth rates, birth records, it is possible to collate them with social and economic -- or with geographic places, let's say the block, a census tract, some other small area for which census statistics are available. Not individual data but for statistics so that if
you want to do some kind of a socio-economic analysis of, let's say, health conditions in the city, you can do them by correlations not with the census information, from the individuals, but census information for the area in which the individual lives.

We have a number of cooperative projects going on with localities. There's one in Indianapolis to explore ways in which this can be done most efficiently.

There is a fair amount that had been written up on this bit where we have a number of manuals to advise people just how to do the geographic coding as well as potential uses, as well as get other kinds of information. If you want to, I can send you a set of materials.

MR. CARROLL: Please.

MR. NISSELSON: You do a great job outside of detection.

MR. WAKSBERG: Yes.

MR. NISSELSON: And that is sent on to the school district for use and now everybody can tabulate the school district.

MR. WAKSBERG: We put school districts code, in effect, on census records. The census records, in effect, didn't have that.

MR. CARROLL: My question was really -- Thank you very much for straightening that out. My question is,
however -- and I wanted to go one step further, Mr. Waksberg -- assuming if one could describe knowledge needs of the population programs, about the population they were intended to affect, could one use information of this sort to get nearly as good usable information that would serve the purposes for which some people argue you've got to match on the individual and develop a positive record?

MR. WAKSBERG: At this point, to get into a definition of what is nearly as usable, I'm not sure I know how to answer it.

Certainly if you want to correlate it, let's say, with health, with social and economic information, you are best or better off using information for the individual himself.

As soon as you go to some broader areas such as geographic areas, you are making some kind of compromise. You are weakening your ability to analyze the data.

Now, we say that this weakening is necessary. You know, because of confidentiality provisions, we cannot hand over information to the police commissioner of Washington, D. C., information so he can correlate his prime statistics, so you're making some kind of compromise there. You can get usable information. How much you lose in this kind of process is hard to state in any quantifiable purpose.

For some purposes, the loss may be trivial. In
others, it may be very useful. I don't know how to answer your question.

MS. GROMMERS: Thank you. That's a very beautiful answer.

MR. NISSELSON: There has been an attempt at manpower training programs by following up people in social security, their earning records and at least in some instances it was not possible to get marginal data but total sets of three data. I believe you can get information about how satisfied people were with that kind of comparison and that kind of evaluation.

MS. GROMMERS: Thank you. You had one point, too, that you wanted to make.

MR. JUSTICE: The discussion we have had today is primarily on some of the things that Mr. Shiskin mentioned earlier and have centered on the question of confidentiality.

One of the things which was brought up in the hearings on the 1970 census, at least in my interpretation of the hearings, is that a lot of people here think the mere extraction of the information is an invasion of privacy.

This would seem to have significance effectively in statistical data banks where once it is statistical, you cannot of course insure the confidentiality. And since we have not addressed this issue of whether the extraction of information is or is not an invasion of privacy and what can
be done about it, I would like to hear some comments on that.

MR. WAKSBERG: I am not sure I understand your question. Is it that the very process of asking for information involves invasion of privacy?

MR. JUSTICE: People feel that being mandated for one reason or another, feel forced to give information which they normally would not give about themselves, that is an invasion of privacy.

MR. WAKSBERG: Yes, it is an invasion of privacy. I suppose society has to reach a conclusion whether the benefits of getting the information are worth the infringement. In some cases, I think there are some kinds of answers. As I mentioned earlier, in the 1970 census, we felt that if we asked for social security numbers, it would enable us to provide some marginal additional information. But we regarded the additional information we got was not that great a value, that it was worth doing.

I suppose you can ask that about almost any question you can ask in the census. At present, Congress has agreed that the loss to the individual is not great enough to make up for the gains for society. Other people can take different points of view.

MS. GROMMERS: Do you think Congress has looked at it in that light?
MR. WAKSBERG: Oh, certainly. These issues of the effect on the individual, both on the point of invasion of privacy and on the burden of responsibility, have been taken up often in congressional committees.

MS. GROMMERS: Could you get us some of the hearing documents?

MR. WAKSBERG: I'm sure we could.

MS. GROMMERS: Mr. Simmons wanted to respond to this, too, I believe.

MR. SIMMONS: I might say that in our case, all of our information is secured on a voluntary basis. Now, it is quite true that we use various devices, some of them perhaps a little settled and some of them not so settled, to persuade the respondent to give the information. But we do also have the principle that we must have his informed consent. He must understand that this is possibly what it is that we are trying to do and this, of course, gives you a delicate operating problem because you do not want to endanger your respondent's right, too.

If I may, let me read a brief paragraph of one of our publications. We are dealing with this question of privacy and confidentiality simultaneously, and we are saying:

"This is an instance of the fundamental proposition that in a democratic society each individual must give up a little bit of his freedom in order to insure that both he and
his neighbors live in a free society.

"To be more specific, the federal statistical information system asks that each citizen truthfully provide to the government on request certain pieces of needed information which he might prefer, for one reason or another, not to report, and to do so in order that the government can carry out its programs more wisely and more efficiently for the benefit and welfare of all the citizens.

"Similarly, even though that government possesses certain items of information, the individual citizen must sacrifice a small amount of his freedom, and be restricted from having access to that information in order not to transgress the rights of privacy of other citizens."

I think that describes our position on that topic generally.

MS. GROMMERS: Could we give that to the stenographer for the record afterwards?

MR. SIMMONS: Yes.

MS. GROMMERS: I have one question that one of our members would love to have addressed to you, Doctor Nisselson, and he is with the Department of Education with the State of Florida.

He says with respect to the longitudinal study of educational effect, data are collected from individuals. These data are maintained with persons identified in some
way, as we heard in some way earlier today, earlier in our meetings.

His questions are, one: What assurances are given to the individuals regarding confidentiality?

Two: Are the assurances, if given, enforceable? For example, under the Freedom of Information Act, are the data subpoenaable?

Three: What measures is USOE taking to assure confidentiality?

And, four: Are measures taken for this weaker, stronger or the same as measures taken with other similar efforts in their work?

MR. NISSELSON: If the comparison is in OE, the comparisons were taken a little stronger.

The assurance we give the individuals essentially are that we undertake to try to assure that we will not release data in the way that individual information could be identified to an individual.

And the devices that we are trying to use to help assure that are of the kind that I talked about earlier. I think that you know we are taking a great many steps which we think, in trying to maintain a kind of discipline, that Mr. Gentile was talking about. We don't have any ultimate sanction though, and it is for that reason that we think that we would like to have legislation of the kind that
Julius Shiskin was recommending for all agencies.

MS. GROMMERS: Thank you very much.

We have one more question and then I think we'd better thank you all very much for coming.

(Private discussion between panel members.)

MR. NISSELSON: Partial monitor. Say, our instructions tell a student that he doesn't have to reply. The response is entirely voluntarily.

MR. CARROLL: I wrote a question out. I originally intended to address it to Mr. Waksberg, but it appeared to me it is an appropriate question for all five of you.

I'd preface my question in saying that the Committee is interested in locating hard data, shall we say serious social science research, on the perceptions that people have of what is private and of the behaviors that are associated with privacy in the contexts that are recorded by people regarding privacy, and the circumstances under which these perceptions are held and they are not.

The reason I wanted to address this to Joe is that the Census Bureau at some point has looked into how the confidentiality pledge is attached to the census and are perceived by the respondents and also, conversely, the money to the respondents. And I wonder if he would tell us something about that for the record and whether these other statistical
centers represented here have done any research of that sort on however large or small a scale.

It would give us some greater insight than one gets in the rhetorical literature about the significance of privacy in an individual's life in certain circumstances today.

MR. WAKSBERG: I am not sure I can give you anything more than other case studies.

I don't know of any real research that has been done to get people's perception either on the general notion of privacy or confidentiality or where they stand relative to the government when the government comes around with questionnaires or whether they are more concerned about earnings in privacy or confidentiality for some items than for others.

We do have hard statistics on such things as refusals in our voluntary service, how many people refuse to give information at all. We have information on how many people refuse to answer specific questions and, there, I might say that the general folklore which is brought out by some is that income is by far the general subject, much more so of what most people will consider private.

MR. NISSELS: What about that experience in business surveys, giving your respondents an explanation?

MR. WAKSBERG: I'm not sure what you mean.
MR. NISSELSON: This was actually a respondent's current business sales. Half of your people gave the explanation why the government wanted the sales last month.

"Why do you want it?"

"I don't know why they want it. I'm just getting paid for it."

The other thing was it was an extra value to the businessmen, and the remarks were remarkably lower which is to pay the respondents, which is self-interest rather than the government wanting it.

MR. WAKSBERG: Let me see if I can answer your question.

MR. SHISKIN: Was that really a survey? I had the story it was a one-man survey.

MR. WAKSBERG: In connection with people's perception as to what the extent is to the government, how confidential is confidential data, we don't have any surveys. But we have lots of impressions around that.

This is sort of a bewildering notion to people and, number two, they are very skeptical when we talk about confidentiality in that we mean it and that there is a general feeling of, "Yeah, we have it in our files. If the F. B. I. wanted information, of course, they will be available to them."

They don't realize that if the F. B. I. wanted it,
they don't find it in our files. It is not a confidentiality
that you have. It is just general bureaucratic ineptness.

But certainly, the evidence that we have is
that people don't really trust these statements of
confidentiality. I shouldn't use the word "evidence."

MS. GROMMERS: If we could get any documentation
on any of this, we would be very grateful. We would like
to have surveys about which questions they did not answer,
for example.

MR. WAKSBERG: Actually, this is tabulated in
all our census volumes in terms of number of responses,
item by item, how many people didn't answer, age; I can
produce a few tables like that.

MS. GROMMERS: But you never investigated why?
You simply tabulated them?

MR. CARROLL: Some of the methodological
tabulations might interest you.

MR. NISSELSON: Different interviewer groups
like the HIP study center.

MR. WAKSBERG: How do you interpret that in the
context of the question?

MR. CARROLL: Oh, Joe, may I call you by telephone
and ask you?

MS. GROMMERS: I think we are going to thank you
all very, very much for being with us and staying with us so
late and accepting our invitation to come back and join us again.

(Whereupon, at 5:30 p.m., the Committee meeting was adjourned.)

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