

ORIGINAL

Transcript of Proceedings

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

SECRETARY'S ADVISORY COMMITTEE

on

AUTOMATED PERSONAL DATA SYSTEMS

Bethesda, Maryland

Wednesday, 26 July 1972

ACE - FEDERAL REPORTERS, INC.

Official Reporters

415 Second Street, N.E.
Washington, D. C. 20002

Telephone:
(Code 202) 547-6222

NATION-WIDE COVERAGE

MACIAS
CR# 6933

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

C O N T E N T S

| <u>PRESENTATION BY:</u> | <u>PAGE</u> |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------|-------------|
| Dr. Marvin Schneiderman, Assistant Scientific Director, Demography National Cancer Institute National Institutes of Health, DHEW | 6 |
| Mr. Harvey Geller, Head, Special Cancer Survey Section Biometry Branch, National Cancer Institute National Institutes of Health, DHEW | 19 |
| Mr. Ted Weiss, Head, Automatic Data Processing Management Section Biometry Branch, National Cancer Institute National Institutes of Health, DHEW | 24 |
| Mr. Julius Shiskin, Director Statistical Policy Division Office of Management and Budget | 127 |
| Mr. John Waksberg | 139 |
| Mr. Sigmund Schor | 199 |
| Mr. John Carroll | 209 |
| Office of Research and Statistics Social Security Administration, DHEW | |
| Mr. Walt Simmons, Assistant Director National Center for Health Statistics | 215 |
| Mr. Harold Nisselson, Assistant Director for Research, National Center for Educational Statistics | 221 |

19

20

21

22

23

24

25

6933
Macias
3 thru
25

3

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

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

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

19 Now, what we have to do is somehow soften just the
20 tiniest bit of that feeling without taking it all away. The
21 suggestions that have been made to me -- I will pass them on
22 to you for what they are worth, which is a lot -- the first
23 is just to tell you all this so that we all know everybody
24 has been thinking about it, that we have to slow down a little
25 bit but that we must very definitely not stop.

1 Second is that I think the process we had yester-
2 day, in the last minute we really were getting a group thing
3 together so that we can now make our responses somehow relate
4 to what the other questions have been and moderate the
5 impression that we are a group, which is terribly important.

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

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

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

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

21 For example, Mr. Small, yesterday, apparently
22 thought that we were much more deeply involved in freedom of
23 the press and things of that kind and then, in fact, we are.
24 We are certainly interested but that is not our main
25 objective.

1 In other words, try to establish for them a
2 contextual framework which should include, I think, a list of
3 the people here, an extremely brief statement as to what
4 their principal interests are. Another thing the witnesses
5 often don't know is essentially who they are talking to.
6 I think that's the main thing.

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

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

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

25 MR. SIEMILLER: I think that it is very

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

6 (Brief recess.)

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

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

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

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

25 Doctor Cox is an old friend. I notice she agreed
that I was not a demographer.

1 On my right is Mr. Geller who is head of our
2 Special Survey Section concerned with the third national
3 survey, cancer survey.

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

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

11 MS. GROMMERS: Please.

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

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

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

25 The National Cancer Institute has, as you might

1 guess from my calling this the third national cancer survey,
2 twice before done surveys of the incidence prevalent in
3 mortality from cancer in the United States in certain sample
4 areas of the United States. Each time, we have done this.

5 The first one was in the late Thirties, 1937,
6 1938, that time, to tie in with the 1940 census; then ten
7 years later, to tie in with the 1950 census, and then we
8 skipped the 1960 census. We did not do a survey around the
9 1960 census.

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

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

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

25 Obviously, there are questions of treatment. If

1 our treatments are successful, we will have very little more
2 mortality. Second, you treat incidence cases in a hospital,
3 in the medical facilities. You want to know how many people
4 are ill who then have to be treated, who then use your medical
5 facilities. Therefore, you have to know how many cases
6 there are.

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

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

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

22 While this is going on, there are changes occurin
23 in terms of the quickness with which a woman will come to a
24 physician to have a disease diagnosed and there are changes
25 going on with respect to treatment of the disease so that the

1 earlier diagnosis largely initiated by the woman herself
2 combined with perhaps somewhat better treatment has kept the
3 mortality of this disease at a relatively constant level in
4 this country; whereas, the incidence is going up.

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

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

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

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

25 Things are happening in the other direction, too,

1 of incidence. Invasive cancer of the uterine cervix, once an
2 extremely important disease of this country, incidence of
3 this disease is going down and going down very nicely. It
4 is going down very steadily and has been going down over a
5 long period of time, going down somewhat more rapidly among
6 blacks than among whites, by the way, over the last decade
7 and a half.

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

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

21 Our survey covers, as you will see from this
22 little pamphlet, several areas of the country including two
23 whole states and the Commonwealth of Puerto Rico. It covers
24 Iowa, Colorado and the Commonwealth of Puerto Rico. We have
25 done these on Iowa and Colorado in order to cover and get

1 some information on rural populations. By and large, most of
2 the work done, cancer studies are done in the vicinity of
3 large hospitals and so, by and large, you will get urban
4 information.

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

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

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

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

23 I think from our data in Puerto Rico, we have
24 very strong indications of where improvements in the way of
25 life changes, in economic status, things of that sort will

1 improve. In other words, reduce the incidence of cancer in
2 Puerto Rico, and then have implications obviously for certain
3 segments of the United States population, segments of low
4 income.

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

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

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

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

22 We hope we can find some information, most of thi
23 relating to the origin of the disease, most of this hoping to
24 give us clues to look into the origin of the disease so that
25 we might then go out and take preventative measures.

1 There is very little being done in this country
2 at this time by way of prevention of cancer other than the
3 anti-smoking campaigns and these have been moderately
4 successful. They have not been successful as we have hoped.
5 There are certain portions of the population who are not well
6 reached by these campaigns. White middle-class people are
7 superbly reached by these campaigns. Apparently, the
8 advertising people who have set these up are apparently
9 middle-class white males, and that's why they are doing a
10 great job on it.

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

23 We have not reached the black population very well.
24 The proportion of black males who are smokers is substantially
25 higher than white males who are smokers. Lung cancer among

1 blacks, black males, is substantially higher than lung
2 cancer among white males. This may be a reflection of many
3 things. I suspect it is a reflection of the kinds of jobs
4 these people have, the kinds of environmental exposures they
5 have, the kinds of personal air pollution as well as impersonal
6 exposure; impersonal through the position and personal to
7 where they work and what they do.

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

12 The sample on this, as Mr. Geller has pointed
13 out to me, there are two aspects of this. This is not cover-
14 ing the whole country quite obviously. We are covering about
15 10% of the population of the United States which, in the
16 cities, in the areas we are covering, in itself is an enormous
17 sample. We are doing it for a period of three years because
18 although we are covering 10% of the population of the United
19 States and cancer is the second most important cause of death
20 in this country, cancer is really a rare disease.

21 So that as I remarked to Mr. Courtney Justice a
22 little while ago when we were talking about this in children's
23 cancer, it is the most important form or the acute lymphocytic
24 leukemia about which our chemotherapists have done a better
25 job of providing better care than before.

1 Acute lymphocytic leukemia will affect perhaps
2 a total of 2,000 children in the country this year. This is
3 the stuff you see in the newspaper. The early Christmas
4 party for Jimmy before he dies before Christmas. This is the
5 disease he generally has.

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

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

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

20 So for that reason, the survey will cover -- and
21 this is the first time we are doing this -- the survey will
22 cover three years: 1969, 1970 and 1971. The 1969 data, as
23 I said, have already been published. 1970 data are well now
24 along, are in publishable form or will be in publishable form
25 by October of this year. But I don't think we are planning

1 to publish these. I think we will now publish the whole set
2 altogether. There doesn't seem to be any good reason to
3 publish another intermediate report now that we have published
4 this one preliminary that you have.

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

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

20 In addition to gathering these data on incidence
21 prevalence and mortality from the disease, we are also attempt
22 ing for the first time to gather data on the economic impact
23 of the **disease** and some of the social components of it.

24 On a 10% sample of the patients identified in
25 this survey with the agreement and approval, **written approval**

1 of the patient's physician, we are gathering further informa-
2 tion in more depth, attempting to give us information on
3 how does the patient eventually get to the physician? How
4 does the patient get into the medical care scheme? How does
5 the patient get into the medical flow of this country? What
6 does the disease cost its patient, its family? What kind of
7 social and economic disruptions and upsets does this lead to?

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

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

16 In other sections of the country, the physicians -
17 and I think this is an aspect in sociology of practice with
18 American medicine -- other sections of the country, the
19 physician has said, "No, I don't want you to talk to my
20 patient. I don't want you to talk to him and not his
21 family. They don't know what is going on. Don't upset them."
22 Then quite obviously, don't go and talk to the patient or his
23 family.

24 We should have publication on some of the
25 preliminary information. We are aiming for October of this

1 year, and I think we will have, really, the first sort of
2 nationwide comparisons of the **costs** of this disease and the
3 patterns of achieving medical care that have ever been
4 published. And as I say, our first reports on that will come
5 in October. We are planning for October of this year.

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

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

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

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

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

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

22 MR. GELLER: There are three basic data gathering
23 forms, or forms for gathering the basic data. One is the form
24 used for hospital records where we have our own contractors
25 going into the hospital and abstracting data from medical

1 records.

2 Another form is used in abstracting the data from
3 death certificates, from deaths that occur in the area or
4 residents of the area, outside that area. And the third form
5 is information from private practitioners where patients have
6 ~~not~~ been into a medical facility, we ask the doctor to fill
7 in the form.

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

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

18 So we use the name and address for this purpose.

19 We also use the name and address in the interview
20 or the sample portion since part of the sample is an inter-
21 view with the patient, we need the name and address to contact
22 the patient although we could sort of not do this. We could
23 ask the physician when we inquire from him if we could
24 interview the patient. These are the two main reasons why
25 we have the name and address.

1 As far as confidentiality of the name and address,
2 in the computer files we have separated the name and address
3 from the basic physical data. We have a separate file that
4 has the case number and address. We have a separate file
5 with all of the data.

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

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

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

19 In addition to separating the identification
20 information and the data so that when the data are put together
21 there is no individual identification in relation to this,
22 Mr. Steele has prepared for you, as a summary of what we are
23 doing, what looks like a very nice statement, a very good
24 summary of what we are doing. And he includes on that, on
25 page six, some of the security aspects of what we are doing.

1 Every employee -- and they are not employees of
2 the Federal Government, by the way -- where we are doing this,
3 out in every area in which we are working on these people,
4 are employees either of the Health Department of medical school
5 or university or something of that sort. Those are our
6 contractors. Every employee has to sign a pledge concerning
7 the confidentiality of the data. Every employee is given a
8 little statement as to why these data are so confidential.
9 Cancer is an important disease. It has emotional components.
10 Don't talk to anybody about anything that you see among these
11 records. You may recognize the name of somebody that you
12 know; don't talk to anybody about it. Don't talk to your
13 husband. Don't talk to your wife. And a little statement
14 on this is to why this is of consequence.

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

23 The Director of the Michigan Cancer Research
24 Foundation in Detroit asked that. Obviously, we can do that.
25 We have done it. We can identify anyone in any way. We can

1 get a range for that, which is obviously a reasonable thing
2 for a man in his area who wants to work on his immediate
3 local problems, to request from a lawyer for a patient who was
4 suing her physician concerning what she thought was the
5 improper treatment for her disease, and he wanted the names
6 of all the other people in her area who had the same disease.

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

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

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

18 So as I say, we get a great range of requests for
19 information. We do have two Advisory Committees and, in
20 general, they have advised us -- what makes great sense to us
21 no identifying information to go to anybody, no matter what
22 the request is. Two, no raw data to anybody even in the
23 unidentified form, provide tabulations in terms of what the
24 people ask for, because even though you might think you have
25 covered everything in terms of confidentiality, sometimes we

1 have produced raw data, especially with rare forms of the
2 disease, you know, there are only three people in the whole
3 community who have had these diseases, you can then identify
4 them.

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

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

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

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

22 MR. WEISS: By the way, that was one of our great
23 concerns at the beginning of the study when we were designing
24 the data processing system, as to how to prevent this kind of
25 thing from happening and we have taken some very -- what I thin

1 are some fairly elaborate procedures to protect the
2 confidentiality of the data in the files.

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

7 Mrs. Cox.

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

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

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

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

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

20 MR. SCHNEIDERMAN: Yes.

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

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

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

24 MR. SCHNEIDERMAN: Our data come from physician
25 records, hospital records, death. The individual patient is

933

1 not contacted ~~except~~ the one who is in the survey.

begin 1

2 MS. COX: Of course, that is fairly general
3 information. That is not going to hurt him. But when you
4 go for the sample, you have got to give some degree of con-
5 fidentiality.

ph 1

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

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

16 MS. COX: Yes, I saw that.

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

25 MS. COX: Just one more question on this previous

h 2 1 paper that came to us. You say there is no formal record
2 kept to whom you give the data. Wouldn't that be advisable
3 and a protection?

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

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

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

11 MS. COX: So far.

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

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

20 MR. SCHNEIDERMAN: No.

21 MR. WEISS: Actually, to date, the people who
22 have been receiving information from us are the field offices
23 themselves or the principal investigators within the field
24 offices. They are the only ones who have received back de-
25 tailed information.

ph 3

1 Other individuals or organizations such as the
2 hospitals that contribute, or the physicians that contribute
3 case information to us receive only tabulation data and that
4 is primarily the data we give.

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

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

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

13 MR. WEISS: We do have a great deal of informa-
14 tion, not in terms of the diversity of the information on a
15 particular case, but the quantity of information, some of
16 it similar information. But there are so many complex as-
17 pects and relationships of each piece of data to another that
18 we are really very reluctant to give out to any individual
19 detailed information. They would have to have a very, very
20 large, very complex manual to understand all of the relation-
21 ships.

22 What we hope to do at the end of the study is to
23 summarize and create and extract files for investigators,
24 qualified investigators to use, where we will very, very care-
25 fully analyze and make decisions concerning the data.

n 4

1 At this particular point in time, most of the
2 information is fairly rough, and we do manage to purify it
3 in order to produce some of the preliminary reports. But it
4 is certainly not something that we feel at this point we can
5 put in the hands of any investigator.

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

10 MR. SCHNEIDERMAN: Yes.

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

13 MR. SCHNEIDERMAN: Yes. In fact, we have two
14 preliminary manuscripts on analytical work on the 1969 data
15 already, and there are plans where we are now discussing
16 with the editor of the journal of the National Cancer Insti-
17 tute, plans for producing either a monograph, journal of the
18 National Cancer Institute, a monograph based on those data,
19 or a series of separate papers, sort of sight oriented.

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

21 MR. SCHNEIDERMAN: On the whole three-year thing.

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

24 MR. SCHNEIDERMAN: The same sampling area.

25 MS. COX: So you can make the comparison?

1 MR. SCHNEIDERMAN: Yes.

2 MS. GROMMERS: Mr. Davey.

3 MR. DAVEY: Pass.

4 MS. GROMMERS: Mr. Gentile.

5 MR. GENTILE: Yes, I have essentially one ques-
6 tion and one comment.

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

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

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

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

18 MR. SCHNEIDERMAN: Yes.

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

23 MR. GELLER: It is contained in that. It doesn't
24 go into as much detail, but we do indicate in the manual the
25 levels of confidentiality, what you are supposed to do in

1 contacting a patient and contacting a physician, things like
2 that.

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

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

5 MR. GENTILE: I'm really talking about all the ad-
6 ministrative as well as the machine and soft ware. I under-
7 stand you have limited access of certain journals, as to what
8 files they have access to.

9 MR. SCHNEIDERMAN: That is right.

10 MR. WEISS: We have devoted a great deal of time
11 and money to the documentation of the system, the editing
12 criteria, the procedures for validating the data, for cor-
13 recting information and so forth.

14 We do have a great deal of documentation avail-
15 able.

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

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

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

ph 8

1 the details of the operation.

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

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

12 He works quite close with it.

13 MR. SCHNEIDERMAN: Someone from our staff.

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

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

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

23 MR. GENTILE: One final comment, Madam Chairman.

24 MS. GROMMERS: Yes.

25 MR. GENTILE: Another one of the concepts that you

h 9

1 gentlemen -- or two of the concepts that have been discussed
2 in this committee and that you are implementing, number one,
3 you have established a set of two files; the identification
4 that is separate from the case abstract and the data on that
5 individual.

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

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

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

15 Professor Weizenbaum.

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

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

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

24 MR. SCHNEIDERMAN: You suggest we would then
25 perhaps go through someone else who knows we are going through

ph 10

1 the record?

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

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

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

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

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

22 MR. SCHNEIDERMAN: In crypt, yes.

23 MR. WEIZENBAUM: I just want to make a little
24 comment on that point on this business of sequestration. I
25 would suggest, even if it isn't necessary for you to do that

ph 11

1 and apparently you have paid very much attention to the
2 generality of the problem it might nevertheless be a very
3 good example and a precedent for other persons to do it.

4 MR. SCHNEIDERMAN: Certainly an intriguing idea.

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

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

11 (Laughter)

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

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

18 Now, isn't that true?

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

22 I would just like to hear your view as to -- I'll
23 use the word "propriety" because no other word comes to mind,
24 that's not really exactly what I mean, that procedure --
25 you know, looking at it now from the point of view that an

ph 12

1 individual patient who goes to the hospital and either --

2 MR. SCHNEIDERMAN: Why should I see somebody's
3 psychiatric record, for example, if the hospital has psy-
4 chiatric records?

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

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

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

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

22 I just wonder what your attitude is of looking
23 at this from the point of view that if the patient who came
24 in to the hospital with implicit or explicit guarantees that
25 his record is not going to be seen the patient is

h 13

1 probably naive with respect to this and probably believes
2 that the record is going to be seen only by his physician
3 and possibly one or two other people -- you see, I am
4 pushing this example thing -- where does one, just like
5 here, in an attitude on your part in your view, where does
6 one put justification down, where even though there may be
7 a legitimate research need and, nevertheless, we have privacy
8 and confidentiality issues, does research justify everything?

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

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

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

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

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

25 MR. WEIZENBAUM: I assure you that --

1 MR. SCHNEIDERMAN: In fact, I was appalled.

2 MR. WEIZENBAUM: Could you respond to --

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

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

10 Cancer is recordable in some states and, there-
11 fore, the work that is done in the abstracting or the data
12 gathering becomes an arm of the local government.

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

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

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

24 MR. SCHNEIDERMAN: In other words, the hospital --

25 MR. GELLER: The hospital pulls the records and

1 files, the medical records.

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

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

13 MR. GELLER: We have had no requests for this,
14 but the question has come up about case studies, in other
15 words, where, as an example of a while back, there was a
16 piece in the newspaper about the vagina in young females
17 where the mother was given Sebatrol during pregnancy some
18 20 years ago, and could we identify cases of people who want
19 to do more detailed studies about this?

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

24 They would have to go back to the hospital and
25 work with the hospital board and the doctors in the hospital

1 to get the cases.

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

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

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

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

15 MS. GROMMERS: Thank you.

16 MS. NOREEN.

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

19 MR. SCHNEIDERMAN: No. These have been destroyed.

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

24 MR. SCHNEIDERMAN: We haven't been able to. They
25 have been destroyed and we are planning to destroy these, too.

1 MR. WEISS: I might add that in effect, each
2 process cycle we go through, we incinerate an enormous
3 amount of material. Nothing is placed in the wastepaper
4 baskets.

5 MS. GROMMERS: With proper air pollution control.
6 (Laughter)

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

14 MS. GROMMERS: One never knows when one's train-
15 ing will come in handy.

16 MR. SCHNEIDERMAN: Yes.

17 MS. GROMMERS: Professor Weizenbaum.

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

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

25 Do you know or have you thought about any procedure

ph 18

1 that would in fact satisfy people that files have been
2 destroyed?

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

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

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

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

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

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

20 There are some interim work tapes at computer
21 centers which we don't have that kind of control over. But
22 we have a fixed pool of tapes that we use at our computer
23 center and fixed pool at our data converters and these tapes
24 are always stored in locked cabinets and we don't allow those
25 tapes to be used outside.

ph 19

1 If a tape becomes in poor condition, we degauss
2 the tape. We erase that. We definitely take steps to do
3 that and insure that it is done.

4 MS. GROMMERS: Mr. De Weese.

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

9 MR. GELLER: The cases are not in a sample. If
10 they come back to the hospitals, the medical facilities,
11 we will get initial reports on that. Obviously, when the
12 patient comes in, the record will be given to the administra-
13 tor.

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

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

25 MR. DE WEESE: So if he would come in for psy-

ph 20

1 psychiatric care, you would get that information through that
2 process?

3 MR. GELLER: Yes.

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

7 MR. GELLER: We have two committees: one,
8 epidemiology committee; this is made up of epidemiologists
9 and statisticians from the government, American Cancer So-
10 ciety and universities.

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

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

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

23 I talked with John Silard about this from time
24 to time. He is a friend and neighbor, and I trapped him
25 into being on a couple of programs -- one program, the

ph 21 1 American Statistics of the Problems of the Ethnic of
2 Human Experimentation, and I haven't succeeded in trapping
3 him into another one of our committees yet, but I will try.

4 MS. GROMMERS: Mrs. Hardaway.

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

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

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

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

23 Since we are coding all the cancer, we can pro-
24 vide them with a code which will save them a lot of time and
25 energy. We are still working on it. We are still not success-

ph 22

1 ful.

2 That was the main purpose, though.

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

6 Would you have any feeling that, if I were,
7 for instance, a welfare patient and depended upon that for
8 my source of income and that I had cancer and became a part
9 of your record, that because I was in the condition of de-
10 pending on the government for my livelihood that that in
11 any way would make my record -- that you would have control
12 over -- any sort of public information that would carry
end belt 13 my name?.

14

15

16

17

18

19

20

21

22

23

24

25

kar 1

1 MR. SCHNEIDERMAN: Not any more than if you were a
2 patient at the Harkness Pavilion at Columbia University -- you
3 know, the big University Pavilion where, to the surgeons and
4 nurses, a patient is a patient no matter what he gets paid
5 for, and in view of what may be changes in the medical econom-
6 ics in this country over the next ten years, it may very well
7 be that everybody gets his care paid for in a similar way,
8 quite apart from his source of income. So I don't think --
9 so as far as I'm concerned, it doesn't make one bit of differ-
10 ence.

11 MS. HARDAWAY: Thank you.

12 MS. GROMMERS: Professor Allen.

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

21 MR. SCHNEIDERMAN: We have had no subpoenas issued
22 on us so far as I know for records. The major thing that is
23 really not under our control are the records at the field
24 offices because they originally belonged to the hospital. The
25 records belong to the hospital, belong to the patient.

kar. 2

1 I think the lawyers are going to be struggling with
2 this for some time as to whose record is this, who does it be-
3 long to, who has a right to sort of let it loose. I anticipate
4 that there will be struggles in relation to that. At least,
5 John Silard tells me there is going to be troubles on that.
6 He is of the mind that the records do not belong to the hospi-
7 tal or the physician. They belong to the patient, and this is
8 an interesting concept which I think might cause some real
9 rows.

10 MR. ALLEN: Would it any way ~~impe~~de your effort if
11 those records, as they came from the hospital, the names were
12 separated from the data and in separate files so that they
13 could belong back to -- so that the same person wasn't account-
14 ing for both the information and address?

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

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

24 MR. SCHNEIDERMAN: Yes. Yes. You've reminded me,
25 the first job I had was an office boy in a large corporation

kar 3 1 and one of my first jobs, I was told, "nobody in the corpor-
2 ation is supposed to know what the other earns," and one of
3 the first jobs I was told to do was to go file the W-2 forms
4 but not look at the names of the people and how much they were
5 earning. You know what that did to me. So it is hard some-
6 times to resist the temptation.

7 MS. GROMMERS: Ms. Lanphere.

8 MS. LANPHERE: Well, sir, my points have already
9 been answered. I just have one quick question.

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

13 MR. SCHNEIDERMAN: We do receive information. Would
14 you please speak to that.

15 MS. LANPHERE: From office visits?

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

23 There also was another sort of substudy of the
24 major study and this is on skin cancer which is a problem,
25 collecting data statistics on skin.

kar 4 1 MS. LANPHERE: I was wondering how you got the
2 number of skin studies.

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

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

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

20 MS. LANPHERE: But the patient for that dermatolo-
21 gist or whatever would not know?

22 MR. GELLER: That's right.

23 MR. SCHNEIDERMAN: That is correct. That is right,
24 unless, of course, he indicated to his people that he was
25 providing this information. Some physicians do do this.

Ref 5

1 MS. GROMMERS: Mr. Impara.

2 MR. IMPARA: Just a question to satisfy my own
3 curiosity in ~~terms~~ of your survey technique. Did you reim-
4 burse any of the respondents, either the hospital personnel or
5 physicians' personnel for participating in this sample?

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

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

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

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

19 MR. SCHNEIDERMAN: Yes. Unfortunately.

20 MS. GROMMERS: Mr. Anglero.

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

24 (Laughter)

25 MR. ANGLERO: And the help is not only because of

kar 6 1 the cancer situation. There are some other things that make
2 it different, even with the weather.

3 Well, you mentioned in Puerto Rico you didn't go
4 through specific histories. You ~~want~~ through the cancer regis-
5 try.

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

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

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

12 MR. ANGLERO: You work with the cancer registry?

13 MR. GELLER: With the cancer registry.

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

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

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

24 MR. GELLER: No. This was even separated from our
25 going to go to Puerto Rico. The only reason for going to

kar 7

1 Puerto Rico, we felt the cancer registry reporting was fairly
2 complete and there would be no problems.

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

6 MR. GELLER: The death certificates.

7 MR. ANGLERO: Also in Puerto Rico?

8 MR. GELLER: Also in Puerto Rico.

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

11 MR. GELLER: No.

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

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

17 MR. ANGLERO: In other places besides Puerto Rico?

18 MR. SCHNEIDERMAN: The same sort of arrangement.

19 MR. GELLER: The data is with the local office of
20 statistics. They provide either a copy of the death certifi-
21 cate or the microfilm file, and they went through and abstract-
22 ed the data of the cancer deaths.

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

25 MR. GELLER: No.

kar 8

1 MR. ANGLERO: Did you provide, in this particular
2 case, the consultation of -- tabulations with all the informa-
3 tion that you get from them, do you plan to do it in all cases?

4 MR. SCHNEIDERMAN: Yes.

5 MR. GELLER: Yes. Yes.

6 MR. ANGLERO: And in all cases, also?

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

9 MR. ANGLERO: I put down the question different.
10 Suppose I have looked at this for a while, at this format, and
11 suppose it is not permissible to get a personal data, identi-
12 fiable data, name, address and all these things from any indi-
13 vidual to make a study like this, how would you proceed? How
14 would this affect your study?

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

18 If a person goes to a physician, the physician re-
19 ports him and he goes to the hospital and the hospital reports
20 him and then he goes to another hospital and that hospital re-
21 ports him, then the pathologist reports him, well, we'd like
22 to call this one. We don't want to call it four cases, but
23 one.

24 Certain information enables you to tie the report
25 to a specific individual, and so for that reason, we need some

kar 9

1 kind of identification.

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

5 MR. WEIZENBAUM: Soundex.

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

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

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

18 MR. SCHNEIDERMAN: It is not impossible, no.

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

22 MR. SCHNEIDERMAN: If this is a universal-type
23 number in the sense that if the individual appears some place
24 else at another hospital which has a different numbering sys-
25 tem, we could tie it to the number in the first hospital.

1 Hence, a number like the social security number, you see, would
2 be such an identifying number and you could avoid using a
3 person's name if you had the social security number.

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

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

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

19 MS. GROMMERS: Mr. Siemiller.

20 MR. SIEMILLER: I am really well pleased this morn-
21 ing with the report of the sensitivity for personal privacy
22 that is being carried on in this particular report or program
23 and rather alarmed at your disclosure of what is happening in
24 Detroit. I hope they don't spread, because if it did, every
25 employer would be charging his employees for the opportunity

kar 11

1 to work in his factory or work place, and I just don't want
2 that to happen.

3 (Laughter)

4 MR. SIEMILLER: That's all I have.

5 MR. SCHNEIDERMAN: Don't tell anybody.

6 MR. SIEMILLER: I won't.

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

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

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

19 MS. COX: Of the descriptive type?

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

23 MS. HARDAWAY: May I ask just one question. Ob-
24 viously, you are a good administrator.

25 MR. SCHNEIDERMAN: Well, thank you.

kar 12

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

7 MR. SCHNEIDERMAN: Well, frankly, none of the de-
8 cisions are made because I am a good administrator. It is be-
9 cause I have a superb staff and these people have set up the
10 whole thing and they have written the detailed manual and they
11 meet regularly on problems.

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

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

21 Dr. John Christian Bailar III who started this
22 thing is no longer with the Cancer Institute but is now one
23 of the directors of the VA and is responsible for most of what
24 you have heard here today, and if you want to commend somebody,
25 commend him, please.

kar 13

1 MR. SIEMILLER: I'd like to observe on that, that
2 one good man at the top can make all the difference between
3 success or failure in any particular program whether it is a
4 business, whether it is a trade union or whatever it is. The
5 one individual that cannot pass the buck, his decisions are
6 most important and it can be the difference between success
7 and failure.

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

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

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

17 MR SCHNEIDERMAN: Raise the federal pay, taxing.

18 MS. GROMMERS: Is there any way --

19 MR. SCHNEIDERMAN: Excuse me for that facetious
20 answer.

21 MS. GROMMERS: No. All right. Is there any way
22 that it could be prevented in light of our inability to raise
23 the federal pay and that your staff and yourself would leave,
24 but nevertheless the requirement for continuing your practices
25 and policies would be met?

kar 14

1 MR. SCHNEIDERMAN: I think it would be possible
2 with the director of the Cancer Institute, but in fact I know
3 in terms of the previous director and the current director,
4 these men are both committed to doing this and to continuing
5 to its completion.

6 MS. GROMMERS: Is there any law that --

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

9 MS. GROMMERS: This is Ms. Hardaway's comment, not
10 me. I was pursuing it here. Is there any way there could
11 be a law in a different way? Are you aware of where the
12 authority for such a law would lie?
13
14
15
16
17
18
19
20
21
22
23
24
25

begin 3

phhl

1 MR. SCHNEIDERMAN: At the moment, the law is
2 permissive rather than obligatory. What exists within the
3 law permits us to do this kind of thing but does not require
4 us to and, in fact, in a sense, I am rather pleased that it
5 doesn't require us to, because this is the last time we are
6 going to do a nation-wide survey of this type.

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

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

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

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

22 MS. GROMMERS: I will read this:

23 "No information obtained in accordance with this
24 paragraph may be used for any purpose other than the statistical
25 purposes for which it was supplied except pursuant to regula-

2 1 tions of the Secretary; nor may any such information be
 2 published if the particular establishment or person supplying
 3 it is identifiable except with the consent of such establish-
 4 ment or person."

 5 These are then regulations of the Secretary?

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

 11 We are acting as his agent.

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

 14 MR. SCHNEIDERMAN: Yes.

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

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

 24 MS. GROMMERS: Including this?

 25 MR. GELLER: No. That manual wasn't in existence

3
1 at the time.

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

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

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

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

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

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

25 I think we went as far as we could for approval

1 before we began the major operations of the survey.

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

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

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

16 We have tried very hard to respect confidentiality,
17 respect privacy.

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

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

25 I would hope that they would make a better set

1 respecting the fights even more than we have.

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

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

7 MR. SCHNEIDERMAN: Yes.

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

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

18 MS. GROMMERS: Mr. De Weese.

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

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

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

ph 6

1 these are the types of general --

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

5 MS. GROMMERS: Yes. Yes, I was. This is in ad-
6 dition to it. This is another kind of question ~~apropos~~
7 same problem.

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

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

13 MR. SCHNEIDERMAN: I think I would, yes.

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

16 MR. SCHNEIDERMAN: And I was resisting.

17 MS. GROMMERS: Mr. Gentile.

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

22 I think these gentlemen have demonstrated that, and
23 I fear that too often, too many of us try to legislate pri-
24 vacy or legislate something into being, and it doesn't work
25 that way.

ph 7

1 We jsut heard yesterday from one of the drafters
2 for the Freedom of Information Act that here is a bill --
3 or a statute that has been on the books for five or six
4 years, and he doesn't really feel it has been adequately
5 implemented.

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

11 I think there is no substitute for that.

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

23 As I say, some of it looked to us like real re-
24 luctance and foot dragging, but it is not all bad. In fact,
25 it has been very good.

ph 8

1 MS. GROMMERS: Mrs. Cox.

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

6 MR. SCHNEIDERMAN: Yes.

7 MS. COX: The Office of Management and Budget.

8 MR. SCHNEIDERMAN: Yes.

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

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

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

18 MS. COX: It is a long ordeal.

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

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

25 MS. COX: And that is the Office we want to be sure

ph 9

1 it is kept in -- of course, all week, like this, too, this
2 committee.

3 MS. GROMMERS: Mr. Anglero.

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

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

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

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

21 Mr. Martin had a question for you.

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

25 MR. SCHNEIDERMAN: There are three things that we

ph 10

1 are trying to get out of this. We are trying to get a base
2 in terms of the total impact of this disease, total number
3 of patients, what kind of disease and, roughly, where it
4 exists so that the medical planners may be able to do their
5 planning for medical facilities.

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

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

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

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

17 MS. GROMMERS: Cost effectiveness.

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

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

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

1 to that.

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

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

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

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

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

25 MR. MARTIN: It isn't part of survey processes or

12 1 institutes of NIH generally to try to determine what the
2 consequence is?

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

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

14 MS. GROMMERS: Terrible. That's terrible.

15 MR. SCHNEIDERMAN: A dreadful question that
16 cannot be answered. If I was the parent of a child with
17 acute lymphocytic leukemia, it is apparent what I would want.

18 But these are the kinds of things we are going to
19 have to look at very much from the cost point of view.

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

24 MR. SCHNEIDERMAN: What alternatives would you
25 propose to me in terms of spending the money our Congress says

13
1 we have to spend?

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

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

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

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

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

17 MS. GROMMERS: That's okay.

18 Would you like to ask some more questions?

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

22 As this was done, with reference to what hazards
23 were you operating such care, the statutory obligation to
24 minimally respect the section -- the relevant section of
25 the act? What incentives, for example, do you think exist

ph 14

1 for one to obtain information and use it for some purpose
2 that you would regard as improper against which you strive
3 to protect, from these insidious methods, care?

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

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

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

17 There is a lot of talk about --

18 MR. SCHNEIDERMAN: Yes, yes.

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

22 I just wonder whether the group has given very
23 careful attention to designing a secure system, or has
24 in the first instance, some idea of where the group was design-
25 ing this in terms of some sense of the risk they are trying
to guard against.

kar 1

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25

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

kar 2 1 just have time for two more. Senor Anglero.

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

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

17 MR. SIEMILLER: Derogatory. We used to have a
18 vice president that wouldn't say that. He used to say "dog-
19 atory."

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

22 MS. GROMMERS: Mr. De Wesse.

23 MR. DE WESSE: Sometimes, I think we forget that
24 the data is completely devoid of any personal identification.
25 It's just facts and figures and can also have a very compro-

kar 3

1 missing effect on individual rights, and I point to this
2 document you just passed out today. In your presentation,
3 you made a specific point that one of the principals or
4 variables in the incidence of cancer are social and economic
5 status, but in this entire report, there is no mention of
6 social status.

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

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

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

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

25 Now, we will have socio-economic information, by

kar 4 1 the way, in some of the later reports. But I, for one, at this
2 time, it is my personal opinion there -- some of my colleagues
3 don't agree with me -- I look upon race in this country at
4 this time as an easily identifiable marker for socio-economic
5 conditions.

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

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

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

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

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

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

23 MS. GROMMERS: What are the possible markers that
24 you could have used? That was one. Presumably, what you are
25 saying is you used it because everybody else has been using

kar 5 1 it, too.

2 MR. SCHNEIDERMAN: I ~~used~~ it because we want to
3 compute rates and we want to compute incidence rates, and that
4 is how you can do it.

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

7 MR. SCHNEIDERMAN: That's right.

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

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

14 MS. GROMMERS: Somebody's got to begin.

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

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

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

21 MS. GROMMERS: We have one more question.

22 MS. KLEMAN: You mentioned on trying to work to-
23 wards matching your records with social security records.
24 Are you planning to or are you in the process of trying to
25 match with any other kinds of records, for example, Medicare,

kar 6 1 Occupational Section files, Census files?

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

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

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

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

21 If we are looking at geographic cluttering or age
22 cluttering as clued to where NIOSH ought to go in where the
23 industrial relations people are involved, in that area and
24 that section, that area might be it. In fact, we had a
25 meeting last Friday on this specific problem.

kar 7

1 MR. GELLER: I want to answer your question. We
2 did investigate the record, the linkage between their record
3 and our records. Some things we would want to look at is on
4 a sample basis. Ours is a ten percent sample. Theirs is a
5 25 percent sample. This match would be small.

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

8 MS. KLEMAN: How much? How much?

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

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

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

15 MS. GROMMERS: Their charge to you?

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

17 MS. COX: It is very expensive.

18 MS. GROMMERS: I would like to ask one final
19 question and we'll have a coffee break. Now, suppose you did
20 change your system, suppose you did go on this plan and you
21 did everything that might prevent -- and since the social
22 security number would be on those files -- prevent unauthor-
23 ized accidental leakage of this information to the Bureau of
24 Vehicles, for example, through a computer terminal, what
25 would --

kar 8 1 MR. SCHNEIDERMAN: Before we go into a linkage
2 system involving the social security number, I would want to
3 be quite certain that there would be very good safeguards
4 against this kind of leakage. I am concerned about it.

5 MS. GROMMERS: You think that is possible?

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

13 MS. GROMMERS: Professor Weizenbaum.

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

19 MS. COX: It is not factual.

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

22 (Recess.)

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

kar 9

1

(Discussion off the record.)

2

3

4

5

6

7

8

9

10

11

12

13

14

15

16

17

18

19

20

21

22

23

24

25

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-

kar 10 1 tioned to me that you would like to see here talked about
2 such and such a topic, and the third point is that many of you
3 thought we ought to get started, actually working on the draft
4 which will be draft number six of the outline. I believe that
5 we could at least get a certain amount of the chapters that
6 we all agree are going to have to be in the report, no matter
7 what final form the report takes and that perhaps staff could
8 start to work on this. Do you all have the outline?

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

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

22 MS. COX: The first one, yes.

23 MS. GROMMERS: David points out that both Guy Dob
24 and Florence were not here, and they have come to me and sai
25 that they particularly want to be sure that it is the poor

kar 11 1 people who are definitely included in our list of people we
2 want to hear from that I was referring to as the subjects of
3 the files and subjects of the Welfare files, for example.

4 MR. SIEMILLER: On that subject, for poor people,
5 are you talking about some of these people who are self-
6 appointed representatives of the ghetto and poor people? Are
7 you talking about actual individuals? I'm in total agreement.

8 I don't have no confidence in these self-appointed
9 representatives of people that we find in our various cities.

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

12 MR. SIEMILLER: We are talking about the share-
13 cropper and those type of people.

14 MS. GROMMERS: The migrant worker's child.

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

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

19 (Show of hands)

20 MS. COX: But I'm not really clear. Not exclusive
21 ly?

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

24 MR. DAVEY: I think some of them who are actually
25 administering some of these systems could be spoken to. It

kar 12 1 would be interesting to talk to some of the case workers and
2 people doing some of these things.

3 MS. COX: At regional hearings?

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

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

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

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

20 MS. LANPHERE: A vocational rehabilitation counsel-
21 or.

22 MR. DAVEY: You know the title better than I do,
23 but their view of the world is quite sometimes different from
24 those of the subjects, than those of the administrators, and
25 I have a feeling -- well, let us balance it out.

kar 13 1 MS. GROMMERS: Could I have a show of ~~hand~~s? Would
2 you all like to have some of these people there?

3 (Show of hands.)

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

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

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

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

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

25 MS. COX: Well, whoever is responsible for that and

kar 14 1 supervises that type of thing.

2 MS. GROMMERS: That supervisor?

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

2534 9 MS. GROMMERS: Pat.

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

kar 15 1 This is just a suggestion.

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

4 MS. GROMMERS: Jerry.

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

9 MS. COX: At least a number of them.

10 MR. DAVEY: Yes.

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

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

14 MS. GROMMERS: What are you talking about?

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

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

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

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

kar 16 1 that --

2 MS. COX: Is time.

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

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

6 MS. COX: No, we can't.

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

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

17 MS. GROMMERS: Gertrude.

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

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

kar 17¹ talking to and --

2 MS. COX: A couple of them.

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

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

15 MR. DAVEY: Flexibility at this stage.

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

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

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

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

25 MR. SIEMILLER: At the most.

kar 18 1 MS. GROMMERS: At the very most. I think we have
2 to have two teams. I think it would be tiring. At least it
3 has been, on me, to have more than one hearing in a short time
4 period. You must have had ~~some~~ thoughts about that. Do you
5 know?

6 MR. MARTIN: As to numbers?

7 MS. GROMMERS: How many people can we interview?

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

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

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

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

19 MR. SIEMILLER: Would you think there is any ad-
20 vantage in that?

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

22 MR. SIEMILLER: You can do it and say you are aski
23 them to come in for information and we will expect that "you
24 will be present an hour" at this and then try to set a ~~schedu~~
25 of that kind.

kar 19

1 MR. MARTIN: You have to --

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

4 MR. MARTIN: Yes.

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

7 MS. GROMMERS: Five systems or five people?

8 MR. SIEMILLER: Five different sets of people givin
9 you information.

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

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

21 MS. GROMMERS: I think that you can --

22 MR. MARTIN: You mean if you are asking the subject
23 of the file, as Frances was saying, to be the witnesses -- th
24 range of questions you are going to ask them is much narrower
25 than the people we have been dealing with and you may be runn

kar 20 1 through more of those in a day than in the case where you are
2 talking to a supervisor case worker? I think it is hard to
3 say in the abstract how many people you could talk to.

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

8 MR. SIEMILLER: Preparation will speed the program
9 through.

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

12 MR. SIEMILLER: Oh, yes.

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

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

18 MS. LANPHERE: I already have. Seventy dollars.

19 MS. KLEMAN: I feel if we know in advance what kin-
20 of people we want, where you want to be, then we can go ahead
21 towards moving expiditiously in getting squared away, getting
22 the people lined up just as it is done on Hill. The Senate
23 and House committees have people wait, and the next person
24 comes along in line and then with the smaller groups, I think
25 things can move quite quickly. I really believe that as long

kar 21 1 as we know as ~~early~~ in advance as possible, then we can do
2 that, having people put together these presentations in these
3 jobs.

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

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

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

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

14 (Laughter)

15 MR. SIEMILLER: It is our turn to go.

16 MS. COX: Let me be a little more specific. I don't
17 know that this is my ~~choice~~, but supposing -- you know I am
18 very interested in welfare and that group, and I would like
19 first to talk to the Welfare officer that can tell me what is
20 going on. I would like to go with the case worker and sit in
21 and listen to what she has. I mean, this is arranged, that
22 you sit right in there and hear what is asked and what is done

23 Now, on the same day, if there was a hospital ~~where~~
24 there was, maybe, one of the branches of the Cancer Institute
25 the person that is not on this level but the persons actually

kar 22 1 operating, to go there and see how they go in and get a record
2 out of the hospital files.

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

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

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

13 MR. SIEMILLER: Yes.

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

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

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

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

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

kar 23 1 in serial and one somewhere else and --

2 MR. SIEMILLER: Wouldn't you like to pick geograph-
3 ic sections of the country to get points of different geograph
4 ic views from different sections of the country?

5 MS. GROMMERS: Yes.

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

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

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

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

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

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

24 MS. LANPHERE: New Orleans is near Dallas.

25 MR. MARTIN: Well, the HEW offices in cities would

kar 24 1 have a capacity to help and --

2 MR. DAVEY: We also have to think what the re-
3 sponses of the cities are again.

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

11 MS. LANPHERE: Puerto Rico, yes.

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

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

22 (Laughter)

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

25 MS. LANPHERE: Everybody wants to show off their

kar 25 1 best.

2 MR. MARTIN: I didn't mean that staff would advo-
3 cate the role it is playing with respect to regional office
4 locations. It would primarily play the same role if it could
5 happily be arranged in Oklahoma, Puerto Rico, Tennessee or
6 wherever else, to also include a stenographic reporter and
7 that we could prescribe what the logistics support is, maybe
8 that could be arranged for us as it would be in a regional
9 office city.

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

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

16 MR. MARTIN: No. We might seek guidance from the
17 regional office and get prescriptions from your office and pre-
18 sumably we would do the same for any member of the committee.

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

21 MS. HARDAWAY: I think this is something we should
22 be aware of.

23 MS. GROMMERS: Mr. De Weese.

24 MR. DE WEESE: I have a small problem with dividin
25 the committee up into two small groups, because our major

kar 26 1 strength is our heterogeneous qualities, and I think we have
2 to be careful when we divide up that we don't lose that es-
3 pecially when we go before the public with all our resources.

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

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

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

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

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

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

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

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

25 MR. SIEMILLER: Somebody of that nature.

kar 27 1 MR. GENTILE: Someone whose privacy has been dam-
2 aged and is engendered against this thing.

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

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

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

23 The many small victims, they professionalize their
24 role. You give them one sort of thing, a distorted platform
25 on which to perform and you are not going to learn everything

kar 28 1 that you already know or you couldn't know if you read the
2 last ten speeches they give.

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

5 MS. GROMMERS: Just one more very important comment
6 from Ms. Hardaway and then let me go on to the other two points.
7 Then we can come back to the others.

end 5

8

9

10

11

12

13

14

15

16

17

18

19

20

21

22

23

24

25

begin 6

6933

ph 1

1 MS HARDAWAY: For cities that have good action
2 news type things that are tied in with local radio and TV
3 stations, they would be an excellent source because their
4 people are having only one go at it and they obviously are
5 willing to have assistance or they would not have called in
6 to the TV station and said, "I'm having this problem," and
7 I believe they have worked with them and they would know
8 if they were reliable or if they were professional complainers

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

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

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

17 Laymen does. Anyone else? Jerry does.

18 These are suggestions we would like to bring up
19 to the floor on other things we would like to have come be-
20 fore our meeting.

21 Juan, do you want to say something?

22 MR. ANGLERO: Yes. I wonder -- and I think this
23 goes along with what Mike said before -- it is the management
24 systems commission, really, as such, where we get some people
25 who give with the systems in terms of how it is to be used,

ph 2

1 how to foster decision-making and they could decide how to
2 control information and a lot of things.

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

6 They have designed some of them . They are
7 here.

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

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

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

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

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

19 But it is in the process for Puerto Rico.

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

22 MR. ANGLERO: PBS. We have a lot of things
23 coming in from that. These people have big insights, views,
24 also. They have done designing for PBS and PFP, Program
25 Financial Planning, and many other things. They are a consul-

oh 3

1 tant to HEW on one of these problems and what they do have
2 is a plan on just how information is needed and is used for
3 decision-making processes.

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

7 Pat.

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

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

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

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

23 MS. GROMMERS: What good is it for management?

24 MS. LANPHERE: They have worked with state, county
25 local, all types of governments at all levels. We found them

ph 4

1 very productive, very useful.

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

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

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

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

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

24 MS. GROMMERS: So they might be trying to pull
25 up a series of cases of systems in which confidentiality

ph 5

1 was promised but in fact not being able to be delivered?

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

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

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

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

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

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

25 MR. ALLEN: Yes.

ph 6

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

4 I suppose Jerry's comment would really have to
5 do with this, too, what work has gone to the study if it
6 was labled as such. Maybe this was hazardous to your pri-
7 vacy for which there was a precedent.

8 Jerry, you had something.

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

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

12 MR. DE WEESE: By lunch.

13 MR. GENTILE: In lieu of lunch.

14 (Laughter).

15 MS. GROMMERS: Jerry.

16 MR. DAVEY: Coming back to this question of pub-
17 lic record information, it seems to me that yesterday, some
18 of the things we learned, particularly statistics that Don
19 had, were much more about following through with respect to
20 cases that were reported back when they were checked out and
21 information had not been sent from the courts to the credit
22 bureaus or to the police stations, there seems to be a real
23 problem, and he indicated it was something in the order of
24 14 percent.

25 My guess is that it would be at least that high

ph 7

1 or maybe even higher.

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

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

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

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

22 I would like to see some information about this
23 type of thing because I think here is an area where very
24 little attention has been paid and I think the payoff may
25 be substantial.

h 8

1 MS. GROMMERS: Could we get at this by asking
2 some of the groups that are doing this? It is an audit
3 procedure that you are talking about, really.

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

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

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

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

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

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

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

20 MS. GROMMERS: One of those. Yes.

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

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

24 MR. DAVEY: And maybe one or two of his chief
25 clerks who know the problem well. You know, there's a lot

1 of material which we would need to know about, why it is
2 the way that it is, and then get their ideas about how it
3 can be corrected because I do not think there is anyone in
4 the court system who is blind to this whole thing.

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

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

10 MR. DAVEY: Yes.

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

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

15 MR. WEIZENBAUM I am out of context.

16 MS. GROMMERS: This is input to the meeting.
17 Juan was suggesting getting some management information
18 systems, this type information available. Did you have
19 any ideas?

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

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

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

1 Russell Acoff.

2 Does anyone here know him?

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

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

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

13 MS. GROMMERS: I think he might be.

14 MR. WEIZENBAUM: Do you know him?

15 MS. GROMMERS: Yes.

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

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

21 MR. SIEMILLER: General? Original?

22 MS. GROMMERS: See what you can do.

23 MR. WEIZENBAUM: I have another name. There is
24 a young lady in the Cambridge area, Brigitte O'Farrell, a
25 very dedicated young lady, and she wanted to help, and she

ph 11

✓

1 said she would begin helping at the most intimate level, the
2 lowest level of the bureaucracy level, talking to clients,
3 for example.

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

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

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

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

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

25 If you will bring that to our attention, we can

ph 12 1 also circulate things like that, books. We can circulate
2 titles like that.

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

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

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

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

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

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

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

25 MR. SIEMILLER: To me, that seems to be one of

1 the most important aspects of our mission.

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

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

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

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

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

15 MR. WEIZENBAUM: Yes. No. 4.

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

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

25 MS. GROMMERS: Yes. It could all be right there.

r' 14

1 However, let me say about this outline now, this
2 is not to be --

3 MR. SIEMILLER: Not permanent.

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

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

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

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

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

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

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

rh 15

1 VOICES: Yes. Yes.

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

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

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

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

end 6

8 (Laughter).

begin 7

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

12 Let me read that. Listing of the types of current
13 and proposed p rsonal data and information systems within the
14 terms of reference.

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

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

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

24 But we, in addition, wanted to look at some pri-
25 vate ones.

1 Next time, we are going to be here, if you
2 all would like to have this, people who can talk about their --
3 what I call the Bank and Security Act. This is the new act
4 which took place the first of July where all your bank ac-
5 counts are not going to be -- and mine -- I don't have a bank
6 account, that's why -- all under social security number with
7 an automatic input to IRS for any transactions over a certain
8 amount.

9 MR. SIEMILLER: \$10,000.

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

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

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

23 MR. SIEMILLER: I am just a poor country boy and
24 went to school in Florida, and I have to have these broken
25 down, these things broken down. Excuse me.

p. 17

1 MR. AMPARA: That's all right.

2 MR. SIEMILLER: And this is of their interactions.
3 Would that necessarily be linking up with the private infor-
4 mation that could be leaked or --

5 MS. GROMMERS: Any way.

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

8 MS. GROMMERS: Yes, because anything that is in-
9 formal today might be formalized tomorrow.

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

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

15 MR. WEIZENBAUM: There goes our unanimity.

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

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

22 MR. GENTILE: I would like to volunteer one of
23 our members, Walter Miller and perhaps one of the attorneys
24 in the group might want to compile or put together some model
25 of legislation that is in existence which might appear as an

18

1 appendix to the report or perhaps anything on equipment in-
2 junctions and --

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

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

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

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

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

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

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

25 MR. ALLEN: I think Arthur was asking for that

nh 19

1 No. 5 part as they bore on HEW a number of times.

2 MS. GROMMERS: The labeling part?

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

5 MS. COX: Currently existing.

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

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

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

25 So I have, across the top, the vehicles: quality

ph 20

1 assurance for systems development, state or department policy
2 bulletins, executive orders, legislator, audit procedure,
3 even data center operations manuals, the kind of policy and
✓ 4 procedure that has been developed and submitted by the National
5 Cancer Institute.

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

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

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

23 MS. GROMMERS: Now, one other thing. In three,
24 numeral 2, current communications, technology, I am going to
25 try to get a good gem for you next time, and the other thing

rh 21 1 is that I can ask the other computer company to bring the
2 computer console method that they have, to bring their con-
3 sole and plug it into the telephone so you can get some idea
4 of real communications on a world-wide survey, if you would
5 like that, for an intervention, but someone has to -- Joe,
6 somebody has to -- we need some real good work on the compo-
7 nets of the environ in which the systems are imbedded.

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

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

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

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

23 MR. WEIZENBAUM: I would say, "artificial data"
24 is not relevant if your definition of current is "now"
25 and say "within 5 years."

ph 22

1 MS. GROMMERS: Is there anything that anybody
2 else would like to bring up right now that you feel cannot
3 wait? If not, I would like to ajourn for lunch so we could
4 be starting back here at 10 after 2.

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

7 Does anybody plan to leave early this afternoon?

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

9 MR. MARTIN: We are scheduled to ajourn at
10 5:00.

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

16 MS. COX: Right.

17 MR. DAVEY: What time will the break be?

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

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

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

23 MR. SIEMILLER: Jerry says 3:30.

24 MS. GROMMERS: Well, can you all be back here
25 at 10 after 2, then? We will have a real short lunch..

1 MR. SIEMILLER: Yes. Why not.

2 MR. DAVEY: Make it 25 to.

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

5

6

7

8

9

10

11

12

13

14

15

16

17

18

19

20

21

22

23

24

25

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. GROMERS:--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

25

1 pressures that appear all over the country for data and against
2 data, and we are almost always simultaneously struggling with
3 people who want to do things, important people who want to
4 do things in one way and other people in the opposite way.

5 For example, at the present time we are simul-
6 taneously or nearly simultaneously dealing with two Congres-
7 sional committees who have very different objectives with
8 respect of paper work.

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

12 I won't describe that authority.

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

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

21 Now, the way the language is worded, I believe,
22 is that it puts the burden of proof on the statistical agenc-
23 ies as they cannot issue something without our explicit ap-
24 proval.

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

26 1 disapprove.

2 We just have to sign.

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

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

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

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

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

21 Now, at the same time, Senator McIntyre who is
22 in charge of the Senate Small Business Committee, is complaining
23 very strenuously that we are approving too many forms and
24 putting too much of the reporting burden on business and he
25 will be introducing a bill very shortly, he tells me -- I had

27 1 a session with him very recently -- which will try to put
2 pressure on us in various ways to reduce paperwork.

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

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

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

13 There is one to understand in data collection
14 programs.

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

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

25 So you have to start off with the acceptance of the

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

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

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

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

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

22 For the business concern, it is costly. So what
23 the statistical efforts have tried to do is utilize information
24 that has been reported for one purpose, and for other pur-
25 poses as well.

P-1 29

1 I will give you some examples of that a little
2 later.

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

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

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

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

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

24 On the other hand, that is often in conflict
25 with the desire to minimize reporting, because if one report

ph 30

1 is confidential -- if you assure a person that his report
2 is confidential, then you cannot allow other people to use
3 it, and that could meet duplicating reporting.

4 So we have these three pressures.

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

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

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

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

24 So what I think is a starting point, the kind of
25 things you need for a balanced program that somehow balances

31 1 off all these requirements, first of all, you have to have
2 well established and accepted criteria for judging the needs
3 for various statistics along with the priority scales because
4 this has to be a very explicit thing.

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

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

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

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

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

22 Third, I think in a tough statistical confiden-
23 tiality, the law has to be very tough. Confidentiality has
24 to be paramount, in my opinion.

25 Now, the law, the confidentiality rules on the law

h 32

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

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

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

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

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

21 Now, to get to the next item, I will come to the
22 fourth point, to get to the problem of duplicating reporting
23 and the reduction of reporting burden, I think you have to
24 have arrangements for the transfer of second data from admin-
25 istrative forms; that is, tax returns, data on health insur-

33 1 ance, welfare programs and so on, those arrangements for
2 the transfers of such data under the conditions of statistical
3 confidentiality described above.

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

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

13 The ones used at that time were those for busi-
14 ness concerns without employees and it was compared to what
15 is done now, a relatively small number.

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

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

24 Now, I think that is a tremendous thing. I just
25 want to sort of get that point across. It is a tremendous

r 34

1 thing that half of the returns in the major census were
2 obtained without any direct census enumeration.

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

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

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

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

17 So that is a very important use of administrative
18 data and we are hoping very much to extend that to the pop-
19 ulation area.

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

23 The mid-decade census reached a level, as we
24 refer to, as a big ticket item and had to go to a very high
25 level committee for approval and it was disapproved.

ph 35

1 Now, we are hoping that through the use of the
2 sample, the two percent sample and administrative records,
3 such as health records, Medicare, school enrollment records
4 and so on, we can provide a proxy for a mid-decade census
5 more frequently.

6 This would be another major use of administrative
7 records. So I think this is a crucial part of a modern
8 statistical program.

end #7

9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25

kar 1 1 Next, I only have two more points, so those of you
2 who are thinking you have a chance to speak, Joe --

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

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

5 Now, third, I think here we get a little more sense
6 of the ground. I think it is highly desirable to have arrange-
7 ments for the routine transfer of a probability sample of ad-
8 dresses for the population as a whole from one agency to
9 another. Let me say this again because this is a very sensi-
10 tive and important issue.

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

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

21 But if you transfer a probability sample of ad-
22 dresses, then all you are transferring, it seems to me, is --
23 well, first of all, you are not transferring any information
24 whatsoever about that address except the address itself. You
25 don't know anything about that address except that it is part

kar 2 1 of a probability sample. But you also know that if you canvass
2 this whole probability sample, that you will come up with an
3 estimate that approximates the universe.

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

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

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

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

kar 3 1 agency has the same mandatory authority to collect those data.

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

5 Now, you will notice -- some of you may have ob-
6 served that I have very carefully avoided discussing, mention-
7 ing establishment of a simple statistical agency which could
8 do a lot of this in one fell swoop.

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

15 So we think a single statistical agency is undesir-
16 able for those two reasons, legally responsive or official.

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

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

25 On the other hand, we know there are very sensitive

kar 4 1 issues regarding various different groups, very action to it.
2 I am here today not to tell you anything but to ask you for
3 your reactions on these ideas.

4 MS. GROMMERS: Thank you very much, Mr. Shiskin.
5 We would like to hear first, before we have questions, from
6 you all, from Mr. Waksberg and then the committee will have a
7 chance to question those gentlemen.

8 Mr. Waksberg.

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

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

22 MR. WAKSBERG: Let me make a few comments on confi-
23 dentiality then, and then hold off on other subjects.

24 MS. GROMMERS: Then you will come back, is that
25 what I understand?

kar 5 1 MR. WAKSBERG: Yes.

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

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

10 We are bound strictly by laws saying that when we
11 take a population census, all of the information is confiden-
12 tial and cannot be given to anyone else. Anyone else being
13 anyone outside the Census Bureau, and that includes the fed-
14 eral establishment as well as outsiders.

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

21 There have not been any issues really involved in
22 turning over anything of this sort outside the federal estab-
23 lishment, but there have been incessant demands on us to do
24 exactly the kind of thing Mr. Shiskin mentioned, which is to
25 select samples of households so other Government agencies can

kar 6 1 do their own studies and can do them independently of the
2 Census Bureau. And most of the really tough issues that have
3 arisen have been at sort of these marginal elements of this
4 whole problem of transfer of data.

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

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

24 I agree from the point of view of efficiency in
25 Government, from the point of view of, are we providing in-

kar 7 1 formation that the agency could not get elsewhere? It is an
2 irrational approach.

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

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

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

21 But we have been taking a very hard nosed point of
22 view in terms of saying that anything collected at all with
23 any of our surveys that we have taken under legislation which
24 requires confidentiality, anything that can be at all defined
25 as relating to information should reflect that point of view

kar 8 1 and this is really, I guess, the only point of which I would
2 differ with Julius on everything he said.

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

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

10 There have been efforts to get census data in the
11 past. In fact, in 1922, the Womens Bureau asked the Bureau
12 of Census to provide a list of the names of women who re-
13 ported. As you see, the Womens Lib hasn't just started.
14 Anyway, the Census Bureau refused and the issue went to the
15 Attorney General and he rendered an opinion which said that
16 that type of census information, that is, the names of the
17 women, nameless women, that was information reported in the
18 census, and that the census was confidential, and that they
19 census data could not be distributed.

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

22 MR. WAKSBERG: I think a more dramatic example
23 was in 1942 where the Justice Department asked the Census
24 Bureau for a list of all the Japanese Americans living on the
25 West Coast who were enumerated in the 1940 census and listed

kar 9 1 as part of the program to move the Japanese -- to resettle the
2 Japanese away from the West Coast. And even under the hysteria
3 of wartime conditions, the Census Bureau refused and did not
4 turn over those lists. You are right. There have been --

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

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

12 So I want to emphasize that we, like the Census
13 Bureau, consider the data collected in the census confidential.
14 Confidentiality is paramount.

15 We do run into questions at the margins, but they
16 are important questions for the successful operation of the
17 decentralized statistical system, and that is why we are
18 pulling them in.

19 MS. GROMMERS: Thank you very much. I think what
20 we will do is have some questions from the committee for Dr.
21 Shiskin. Would you like to start, Ms. Hardaway?

22 MS. HARDAWAY: Yes. Mr. Shiskin, I will ask, when
23 you refused to give that information a year ago, was that by
24 an administrative decision of your own, or were you strictly
25 going by your administrative decision?

kar 10 1

2 MR. SHISKIN: Well, they came to my office and the
3 asked us and that was a very easy decision to make. We knew
4 what the law was. We knew the confidentiality provisions of
5 the census and it seemed very clean-cut. We had no difficult
6 on that ~~one~~ at all. We just straightforward said, "It is
7 against the law, against the decision of the Attorney General
8 and the answer is no."

8

MS. HARDAWAY: Thank you.

9

10 MR. WAKSBERG: I would gather from your question,
11 you sort of implied what if somebody else had been --

11

MS. HARDAWAY: Yes. Yes.

12

13 MR. WAKSBERG: If Mr. Shiskin or anyone else had
14 reached a different conclusion, it wouldn't have made any
15 difference because the Census Bureau would have refused to do
16 it in any case because we would have been breaking the law.

16

MS. HARDAWAY: Thank you.

17

MR. DE WEESE: I'm going to pass.

18

19 MS. NOREEN: On these sheets that you gave us, you
20 mentioned that a tough policy is geared toward confidentialit

20

21 I was wondering what you would consider a tough
22 policy.

22

MR. SHISKIN: On confidentiality?

23

MS. NOREEN: Yes.

24

25 MR. SHISKIN: Well, what I think is a tough policy
is the one I just enunciated: no information collected under

kar 11 1 conditions of confidentiality can be transferred to anybody
2 at all outside the federal establishment. They can be trans-
3 ferred to others only under certain circumstances such as
4 those described in the Federal Reports Act which is as follows
5 -- now, let me describe this experience which was some years
6 ago. This was after World War II.

7 The office of Emergency Planning asked the Census
8 Bureau for the names and addresses of certain manufacturers
9 and certain information about those manufacturers. Now, they
10 themselves, the office of Emergency Planning, had the same
11 authority as the Census Bureau to collect those information
12 and they would have gone out and collected them.

13 Now they, also under the law, had strict -- were
14 required to maintain the same kind of confidentiality as the
15 Census Bureau.

16 So my predecessor in this job directed the Census
17 Bureau, under the authority of the Federal Reports Act, to
18 transfer that information to the OMB, and that was done. So
19 I think this is consistent with the strict confidentiality
20 law.

21 Now, you come to this point that Mr. Waksberg and
22 I have been touching on, the transfer of addresses. Now, then
23 I don't really know, I am inclined to think, personally, that
24 if it were up to me and I had to decide all by myself without
25 worrying about any outside reactions or laws, I would consider

kar 12 1 a probability sample of addresses as not confidential.

2 But this is such a sensitive issue that we wouldn't
3 take that position without extensive consultation and, perhaps
4 in the end, we will have to go through the Attorney General
5 for a ruling.

6 So I guess what I have done is to try to describe
7 what I consider to be a clean-cut case of transferring data
8 under conditions of strict confidentiality and a marginal case

9 MS. GROMMERS: Mr. Shiskin, we have a question from
10 staff that I would like to address to you.

11 When Census and OMB have a dispute over the trans-
12 fer of information, who ultimately decides? And must it be
13 referred to the Attorney General, or is there any other avenue

14 MR. SHISKIN: Well, let me say that the marginal
15 returns -- I would like to start this off with a preparatory
16 remark that I was at the Census Bureau for 24 years. But the
17 marginal returns many times have been greater in the last three
18 years than any three years of my life, and the reason is that
19 I am dealing with the top policy people in the Federal Govern-
20 ment.

21

22

23

24

25

end of
belt 68

begin 9

ph 1

1 One of the things I have learned is that within
2 certain bounds, you know these questions depend upon a power
3 structure, and if there were an issue like that and it was
4 clearly to the interest of the government to get the data
5 transferred and the head of OMB was in a much stronger po-
6 sition than the Secretary of Commerce, the data would be
7 transferred.

8 So that is the real world.

9 Now, let me come to the theoretical world. You
10 see, that was the real world.

11 Now, if we really push this issue and Mr. Schultz
12 thought it was best to move the data, I think the data would
13 have moved. That is my opinion.

14 Now, of course, there are other avenues and that
15 is the press, Congress. There can be a fuss, but that is the
16 way it can go. That is the real world. But we don't want
17 to do those things and we don't.

18 Now, what has happened and what can happen and
19 what could happen is that the Census has possession of the
20 physical data, not OMB.

21 So if we direct them to transfer the data, you
22 see, then we can use this power. But we don't want to do
23 that. Generally, it is rare that we do.

24 So what we would do is go to the Attorney General
25 and ask for a ruling. He would have to, just as the Women's

ph 2

1 Bureau in 1922.

2 So that is the course you can go, too.

3 MS. GROMMERS: Thank you.

4 Professor Weizenbaum.

5 MR. WEIZENBAUM: I am a little puzzled now of
6 what I heard about the real world but we don't want to live
7 in that world. It is enormously puzzling to me.

8 MR. SHISKIN: Let me try to clarify it, that is,
9 if you are finished with that part of the question.

10 MR. WEIZENBAUM: Let me clarify my puzzlement to
11 you. I understand about the real world and the not real
12 world, I think, It would suggest that you ultimately rely
13 on the President, that is, if he put the Secretary of Com-
14 merce in a more powerful position, then the Secretary
15 of Commerce could exercise more leverage and could get it
16 done and things of that kind.

17 My impression is that if the Bureau of Census
18 doesn't want to give the information in the real world, it
19 isn't going to be given even if the Attorney General says
20 it is to be given, like a great many orders given in the
21 government which were not obeyed by the Civil Service.

22 However, I am puzzled about that. I think we
23 could spend a day on it and it is fascinating. I am sorry
24 we opened it up.

25 MR. SHISKIN: Let me make one or two more remarks.

ph 3

1 I guess I didn't put that well.

2 What I had tried to say is, well, it is a power
3 structure and there are a lot of things under the power
4 structure, particularly these marginal situations.

5 We professional civil servants do not like to
6 do that and we do not do it, you see. What we try to do is
7 follow an orderly process and that is what we do.

8 That is, so that we could use the route to go
9 to the Attorney General in this instance.

10 Now, I would like to say that that is not a
11 simple thing as it sounds, either, because for one thing,
12 my experience with the Department of Justice is that they
13 are extremely busy people and they often do not have the
14 time to do the kind of research that really should be done
15 in connection with these problems.

16 I very recently have been talking to some of
17 them about this issue and they work on issues here for one
18 day or two, and then they go on to something else.

19 I am sure that there is no attorney in the Justice
20 Department who understands the implications, the sensitivities
21 of these problems as well as Mr. Waksberg and I do, and
22 yet, they are the ones who would be doing the ruling.

23 There is one other point, which is, if an Attor-
24 ney General -- if the decision comes to the Attorney General,
25 this could get into the press and into Congress and you could

ph 4

1 have a trial not on an issue -- not on the merits only, and
2 you could have a big debate and in the press before the issue
3 is resolved on the sensitive issue.

4 I do think it is so important. It is so impor-
5 tant in resolving these issues as to not only have very
6 thorough discussions among ourselves but to deal with people
7 on our own statistical policy, which incidentally includes
8 eight past presidents of the American Statistical Association.

9 It is sort of a round-the-table discussion of
10 the profession. So we have had long discussions with them,
11 but also with groups like this one so that before the issue
12 goes to these great units of power or gets involved, goes to
13 even the Attorney General, we would like to have all this
14 thought out, all discussed fully with knowledgeable profes-
15 sional people in the feild.

16 Does that help in any way?

17 MR. WEIZENBAUM: Yes. Thank you.

18 Let me get to some perhsps less fascinating
19 questions.

20 Two major points you made, one was -- to quote
21 you -- you talk about this and said confidentiality is
22 paramount, in your mind. That is a very big word, paramount.

23 You also talked about the necessity to demon-
24 strate the need for the information if one desires to collect
25 I have two questions about that. One is, how is that need

-ph 5

1 in your survey, how is or how ought that need to be jus-
2 tified?

3 That is, for example, if somebody says three times
4 that "I need it and I really need it," is that a better jus-
5 tification than saying it just once?

6 Secondly, I happen to agree with you as to the
7 need that it is of a paramount nature, the confidentiality.
8 But I am interested in asking you why you think it is para-
9 mount?

10 MR. SHISKIN: Why I think confidentiality is
11 paramount?

12 MR. WEIZENBAUM: Yes. So there are two questions
13 here. One is how is the need demonstrated, or how ought it
14 to be demonstrated to you? Secondly, why do you feel that
15 confidentiality is a paramount issue?

16 MR. SHISKIN: Well, let me take your questions
17 in order.

18 I think that in order to demonstrate need, we
19 have to start off ourselves with a priority scheme for coll-
20 ection of data. Now, we have such a scheme. We have
21 developed it and it is published. It was published in last
22 year's budget and possibly the one in the year before.

23 We have listed what we think are the most im-
24 portant data requirements, you see. Now, the first single
25 most one, the first on all of this is the need to improve the

ph 6

1 GNP figures.

2 Now, the reason I say that is that I know from
3 direct personal experience that your GNP figures into,
4 directly, decisions on major economic, financial -- monetary
5 financial policy decisions.

6 So --

7 MR. WEIZENBAUM: Excuse me. A question back
8 there. When you say "need to improve the GNP figures," you
9 don't mean to have them grow but need to have them precisely?

10 MR. SHISKIN : What was your question?

11 MR. WEIZENBAUM: When you say "need to improve
12 the GNP figures," it sounds like we have been growing them
13 more than ever, not exactly --

14 MR. SHISSIN: Well, for example, the retail scale
15 makes up 30 percent of the GNP on the opposite side. Now,
16 we have got to have very accurate statistics.

17 MR. WEIZENBAUM: I see. So it is economic
18 management you are talking about?

19 MR. SHISKIN: So we have a whole scale like that
20 and they have them scaled and I am sure there are disagree-
21 ments on what our priority scheme is.

22 Other people have them, but we do have them,
23 too.

24 Now, social and program statistics are in that
25 scheme, so we have that.

ph 7

1 Now, when a form comes to us, we review it in
2 the light of those criteria, and on the form itself, we have
3 on the form itself the proposal to us, the commencement of
4 ~~manhour~~ requirements for filling out the form, how much
5 time it will take for the respondents to fill out the form.

6 So we have certain data that were inadequate
7 but it is not an aimless process in answering your specific
8 question that 80 times is any better than saying it once.

9 Now, to get back to this real world issue, I
10 wouldn't deny that a lot depends on who says it, too. Some-
11 times we have to go along with these people that we don't
12 like to go along with.

13 Further, you run into this kind of a situation.
14 We just ran into a major problem that has led to a very
15 large amount of reporting from business.

16 Last year, Congress passed a law on occupational
17 safety and health. Now, this law requires very detailed
18 record keeping on the part of every establishment of the
19 United States and has led to a very large increase in the
20 record keeping and reporting burdens and we are getting an
21 endless amount of complaints about that.

22 Did we get this from the business community?

23 Now, our answer to that is that there is a law
24 on the books. The law was passed by Congress and signed
25 by the President. We can't use the Federal Reports Act

ph 8

1 to countermand a law when the Justice Department comes to
2 us with a request for forms to get that information.

3 We can try and simplify the questions and somehow
4 use our expertise in improving the form of the questions and
5 things like that. But we have got to improve the form.

6 So this is a way of answering your question.
7 We do have these criteria. We do require not only justifi-
8 cation in terms of explanation from these people who are
9 proposing the form, but we also require them to provide us
10 with a statement of the number of manhours required by
11 respondents to fill out the form.

12 We recognize that laws have to be observed and
13 we are first to observe them. So these are the kinds of
14 an atmosphere in which we review the forms.

15 I understand, by the way, that Roy Larry who
16 was on our staff was here and he discussed some of these
17 problems.

18 Well, I think confidentiality and the privacy
19 are paramount. I enter a more philosophical ground because,
20 you know, in a free society, I think the rights of an indiv-
21 idual are extremely important.

22 We have to observe them, and when you go to him
23 for information, I think you have got to make a bargain
24 with him that you are not going to tell anybody. So I think
25 this is just part of our kind of a society.

ph 9

1 I might tell you of a very interesting interchange
2 that took place a month ago or so at the Conference of
3 European Statisticians which I attended in Geneva, and I
4 had the great pleasure of meeting David Martin on the plane,
5 spent half the night talking about these problems.

6 I still haven't recovered. You know, we had
7 a very interesting exchange and I think it might be worth
8 your time for me to tell this little story.

9 This issue was on the agenda, the Conference
10 of European Statisticians. The Conference of European Statis-
11 ticians is one of the regional bodies, regional committees
12 of the United Nations Statistical Commission. There are
13 several such, agency groups; African groups, European groups,
14 we belong to a European group and it is a very good group
15 of people who try to get together the top statisticians in
16 Western and Eastern Europe.

17 Now, this subject was on the agenda, and as a
18 paper prepared by Tom Lyndon of Ireland on the subject,
19 that was a basis for discussion, and that paper will be pub-
20 lished in the August issue of the Statistical Report and
21 some of you may -- oh, I guess it has been distributed, so
22 you already have it.

23 MS. GROMMERS: We would like to have copies.

24 MR. SHISKIN: Well, David can get those for
25 you but I think you already have them.

ph 10

1 MR. MARTIN: They have been distributed.

2 MR. SHISKIN: At that discussion, it is very
3 significant that only the Western European countries and the
4 United States spoke. The Eastern European countries did
5 not participate in any discussion in full. It was a very
6 lively discussion and went on for three or four hours.

7 We just sort of cried on each other's shoulders
8 of all the kinds of problems we had -- by the way, more
9 in Europe than here.

10 Well, now, the way those meetings operate, or
11 work, is that before any meeting closes, usually three or
12 four days -- this one lasted a full week -- there has to
13 be a completed report.

14 Otherwise, of course, there would never be a
15 report. We couldn't get it out in time.

16 Now, when we were reviewing the report which
17 the Secretary prepares at night, by the way, for each day's
18 meeting, there was one expression in there as follows.

19 It was generally agreed that enumerators for
20 the Census should be selective and from neighborhoods outside
21 the enumerated area.

22 Now, we all agreed to that. The U.S., the Danes,
23 the Swedes, the Irish and so on and so on. And it was just
24 agreed to. But during the discussion of the report, the
25 Russian delegate objected to it. He said he did not agree

ph 11

1 to it. He did not speak to it at all and the other -- all
2 the other Eastern European representatives expressed opposi-
3 tion to that statement and what they explicitly said is that
4 they think the ~~enumerators~~ should be selected from the
5 districts in which they live, that is, they should be coming
6 from those districts because that is the only way you can
7 assure accurate reporting.

8 So you see, I come back to this in that I think
9 in a free society like ours, you have to give your people
10 that confidentiality.

11 MS. GROMMERS: I think we'd better go on to
12 the next question, because we have to finish it at 10 after.

13 Mr. Gentile.

14 MR. GENTILE: I have a few questions.

15 Number one. Within the past one or two years,
16 the governor of Ohio wrote or signed a 65-paged letter to
17 President Nixon listing all of the various reports that are
18 required by the federal government for states to respond to,
19 and you mentioned earlier that you accept as an axiom that
20 the people who have the need use it and they come to you and
21 you go out and approve their forms.

22 My question is, how did OMB -- I assume -- OMB
23 got that letter for response -- how did OMB respond to that
24 letter?

25 MR. SHISKIN: I was involved or our office was

ph 12

1 involved in it.

2 I didn't do it, personally, but one member of
3 my staff worked on that and I am not sure I can report
4 accurately. But just what I can conclude is that we did
5 respond to that letter and you could get that response and
6 I could find it for you later.

7 But let me see if I can dig out in my memory
8 where we came out on that.

9 First of all, we thought the government had a
10 legitimate complaint that we had not done a good job in
11 reviewing those forms, and we set up a task force to take
12 another look at it, and I believe that we have cut out a
13 substantial amount of the reporting required from the
14 states.

15 In general, we have not done a good job in the
16 past in reviewing forms that were required from states.
17 I think if my memory serves me correctly, we found a lot
18 of -- what he was reporting was time spent by a state employ
19 well, my memory doesn't go that far.

20 But, in general, we found out he had a good poin
21 and we tried to clean it up and we don't really -- well, we
22 do it but we don't do a perfect job.

23 MR. GENTILE: Can I conclude from that that you
24 did not accept as axiomatic anybody that is submitting these
25 forms actually have a need and a use for it? It is not a

ph 13

1 matter of forms design?

2 MR. SHISKIN: Certainly not.

3 MR. GENTILE: It is a need for the data as well
4 which gets you into their program areas?

5 MR. SHISKIN: Well, we have got to be careful
6 there, you see. We don't want to use our power in the
7 Federal Reports Act, through the Federal Reports Act
8 to review needs for programs.

9 Now, suppose there is a program ~~that~~ has been
10 agreed to, congressional laws as I have said before, and
11 some statement of some agency wants a program.

12 We are not going to hold it up, so their pro-
13 gram -- just because of our authority to collect data. So
14 in general, when an agency has a program in accounting, we
15 will axiomatically accept their program.

16 We agree to have that program, a program. How-
17 ever, we reject a great many forms.

18 So it is clear that we don't axiomatically ac-
19 cept the statement of any data as such. I want to add just
20 one point to that statement I just made.

21 If you will look at our records, these are
22 the records that all Larry keeps. You don't find many
23 forms rejected because it really comes to this point. It
24 really comes to the point that the agency comes to us with
25 a form and we reject it.

ph 14

1 Well, what happens is that when the agency
2 wants to get information, we look at the form and we talk
3 to them and, most of the time, when either the agency doesn't
4 need the data or it is collected by somebody else, they
5 withdraw the form.

6 But there is no data -- we have a big impact on
7 on form collection, though. There are many areas where
8 we don't do a good job.

9 MS. GROMMERS: May I go on? I think we have to
10 have a chance for everybody to ask Dr. Shiskin and Mr.
11 Waksberg a question.

12 May I ask you both just to give an absolutely
13 shorter response so everyone gets a chance for their brief
14 meetings -- questions?

15 We hope to get you back very soon.

end 9

16 Mr. Davey.

17
18
19
20
21
22
23
24
25

kar 1 1 MR. DAVEY: Yes. Let me go through a sequence of
2 events and I would like your counsel on this which raises the
3 whole issue.

4 Assume I am in a particular agency that would like
5 some information from income tax returns and using your point
6 IV or point V, say it would be useful to have for something
7 or other, and use address information or something of this
8 nature, then this information would be transferred to this
9 other agency. And now, this agency, because of its nature,
10 is not able to protect the data as completely as maybe Intern-
11 al Revenue Service would be able to protect their data and
12 someone is aware of this type of a study and comes either
13 through the open end information action or subpoena action or
14 something like that and wants to get this information and
15 somehow or other gets this information using the address as
16 some kind of a key and as they will tie that address into,
17 say, a situation where you go into a city and get one of these
18 directories, street directories, and be able to match up the
19 names quite readily with this address -- now, I think I cover
20 a number of issues that are maybe bothering us -- but could
21 you comment on these?

22 MR. SHISKIN: First of all, I should have made it
23 clear that under the Federal Reports Act, we do not have
24 authority over tax forms at all.

25 MR. DAVEY: Take another agency then.

kar 2 1 MR. SHISKIN: That is a very big issue because the
2 tax forms represent a large percentage of the reporting and
3 one of the things Senator McIntyre is trying to do is change
4 that so we would have authority. Also, of course, let me
5 remind you that he wants to transfer our function out to
6 legislative or executive branches and -- well, so the Secre-
7 tary of the Treasurer has to do that.

8 Now, we happen to be involved with them right now
9 in such an issue and he and we insist that when this authority
10 is granted to another agency, that they establish strict rules,
11 strict confidentiality rules, at least as strict as IRS.

12 Furthermore, the Secretary of the Treasury has been
13 insisting that the other agencies demonstrate that they have
14 appropriate physical facilities to protect the forms, you see,
15 against criminal acts. It is one thing of confidentiality,
16 but there is another kind of problem that people still face,
17 including forms. So my view is that when a form gets trans-
18 ferred --

19 (Inaudible due to noise interference by microphone
20 system.)

21 MR. SHISKIN: --strict confidentiality when the
22 census is prepared itself. Is that responsive to your question?

23 MR. DAVEY: A bit. How about the situation where
24 somebody comes and says -- I forget the name of what we talked
25 about yesterday. Freedom of information?

kar 3 1

MS. GROMMERS: Public information.

2

3

4

5

6

7

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.

8

9

MR. SHISKIN: I think that's right. I think that's correct.

10

11

MR. DAVEY: It is a kind of situation of where we are now, this kind of situation.

12

13

14

15

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.

16

17

18

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.

19

20

21

22

23

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.

24

25

One thing we do under the Federal Reports Act is we insist that when the agencies write a law, establish the

kar 4 1 form, make it clear whether the form is going to be confiden-
2 tial or not, and we also look at their confidentiality laws.

3 Now, in general, I think the confidentiality laws
4 leave a lot to be desired. What we are hoping is that we can
5 get a uniform confidentiality law passed for all physical
6 agencies.

7 Now, I gather from our attorney, we cannot have a
8 single law passed that would do that. Each department is to
9 get their own law. But again, let me say that the only law
10 I consider satisfactory is the Census Bureau.

11 MR. DAVEY: I'd like to continue but will give up
12 my time.

13 MR. SIEMILLER: You used it.

14 MS. GROMMERS: Would OMB issue a better confiden-
15 tiality law for IRS as well as --

16 MR. SHISKIN: I can't speak for OMB and IRS and
17 all its ramifications.

18 But in terms of IRS -- let me answer your question
19 this way -- that we would like to see the census law be, in
20 effect, legal through Congressional action for all agencies'
21 publications in existence including the IRS statistics.

22 For other than the IRS, I don't feel I can speak
23 for OMB.

24 MR. DAVEY: How about in the meantime, what do you
25 recommend for civil laws such as these if passed during this

kar 5 1 interim period, assuming that laws can be drafted and passed?

2 MR. SHISKIN: Well, first of all, as I said, we are
3 urging the agencies to take a look at their laws and then,
4 secondly, I guess what I recommend is that they should not
5 promise more than they can deliver and they should make it
6 clear to respondents that we are insisting on this. We are
7 having all sorts of problems because -- we have had a major
8 problem, for example the water pollution this year, where the
9 issue -- and some of you may have heard changes about our
10 holding up a pollution form for seven years. Well, it is true
11 that the dispute went on for seven years and we did go on for
12 seven years and the reason why is that we insisted that the
13 Interior Department make it clear that the respondents were
14 not being promised confidentiality. That was the issue, and
15 we wouldn't approve the form until they did make it clear.

16 So my answer to your question is that we insist
17 that agencies do not promise more than they can deliver and
18 make clear what they are promising. But that is in the inter-
19 im, maybe, and I haven't thought about it, myself. But the
20 main thing is to get confidentiality laws on the books.

21 MR. GENTILE: Can some of this be accomplished by
22 federal regulations that are within the rights and authorities
23 of OMB since it is the OMB now that has the management and
24 responsibility?

25 MR. SHISKIN: No. It is a Government of laws. It

kar 6 1 is a Government of laws. You have got to get the laws on the
2 books.

3 Now, if an agency doesn't have a strong confiden-
4 tiality program, then they can have an administrator ruling
5 on that. You see, many agencies have that, but that is not
6 as strong as the law. I don't know about that, if that gets
7 challenged under the Freedom of Information Act.

8 But there is even another kind of situation. Sup-
9 pose a Congressional committee comes in, the federal agency,
10 and says, "Look. I want to know what this man is doing."
11 The director of the Census would certainly say, "I can't tell
12 you."

13 But a man who has based it on administrative regu-
14 lation, I don't know if he could get away with it.

15 So I think you have got to get the laws in the
16 books. That is my answer to that.

17 MS. GROMMERS: The next question is from Ms. Cox
18 who is past president of one of those Brahman organizations
19 we were speaking of.

20 MR. SHISKIN: I am aware of that.

21 MS. COX: Yes. I served on that committee until --

22 MR. SHISKIN: Did you resign or did you --

23 MS. COX: I resigned, finally. I resigned, finally,
24 from it. Well, let's don't say why.

25 I would like to pass and have an opportunity after

kar 7 1 some of the other agencies, besides the Bureau of Census, have
2 made their comments because mine applies across the board.

3 MS. GROMMERS: All right. I would just warn you
4 that some people may not be here. That is the only problem,
5 and in light of that further information, would you still wish
6 to pass?

7 MS. COX: Well, I don't know. I will just ask the
8 agency I refer to to excuse me. I am serving on the committee.
9 I know that constantly we were trying to avoid getting dupli-
10 cate information and various agencies getting duplicate in-
11 formation. But this sort of leads into the linkage question
12 and how much of that linkage is being done.

13 I read memorandums and I get an impression that
14 much more linkage is going on than I had realized.

15 Now, the Bureau of Census has strict confidential
16 rules. They have to make certain commitments.

17 Supposing another agency similar to the National
18 Center for Health Statistics feels that they have to give their
19 people a promise of confidentiality, you are giving me some
20 doubt as whether they can back that up or not. But they never
21 would get a lot of this data if they didn't promise confiden-
22 tiality. But interagency wise, you allow a census office to
23 have IRS -- or some of these others, welfare data -- I'm coming
24 back to the right of the individual -- the Census makes a
25

kar 8 1 commitment, the National Center for Health makes a commitment,
2 and you see no difference in interlockings. Is the individual
3 notified when they give the census information that this is
4 confidential for census purposes?

5 The other agencies make it clear it is confidential
6 for their use, but does the individual know when you use it
7 for some other purpose that has linkage?

8 I mean, there is a code of ethics we talked about.
9 The individuals have a right to know that it is not only being
10 used for census but it is being used for welfare, for internal
11 revenue, and what protection does the individual have, and
12 do you have an obligation to get permission from your individ-
13 uals before you pass it on to other agencies? Because we know
14 as soon as you begin to link, even though it is to what you
15 call statistical group data, that you are losing confidential-
16 ity as soon as you begin to cross over these very sensitive
17 medical records and you have it by regions, you have it by
18 areas, and you it broken down into your census divisions --
19 all that, that you lose confidentiality. Both of you lose
20 as soon as you begin to cross it and everybody has the right
21 to know that.

22 I mean, we have talked about a code of ethics for
23 the individual. Now, you instruct on what the law says, that
24 it must be confidential. But unknowingly or just by your
25 linkage, your discipline, do you --

kar 9 1 MR. SHISKIN: Well, Dr. Cox, I don't know who you
2 are addressing this to.

3 MS. COX: Well, the Bureau of the Budget, really,
4 and Walt Simmons over there. Of course, you may be the one
5 that this is addressed to because it is the Bureau of the
6 Budget -- it was the Bureau of the Budget when I was on there
7 -- that tries to get this interlinking and we are always
8 trying to get certain things done by the census and other
9 things by the action agencies.

10 MR. SHISKIN: This is a good issue, and one of the
11 other things, Madam Chairman, that has failed to take place
12 in the last hour is that the committee has been asking me
13 questions but they have not given me any advice. I thought
14 there would be some exchange here.

15 MS. COX: Well, you can turn this around.

16 MR. SHISKIN: What I talked about, I would like to
17 know what you think about this.

18 MS. COX: It is only the way you look at it period.
19 You can turn it around and look at it.

20 MR. SHISKIN: Let me say this. The conditions
21 under which we have transferred data in the past -- and we
22 have used this authority very sparingly -- we have --

23 MS. COX: I understand.

24 MR. SHISKIN: A lot of things take place without
25 our participation, sparingly, but the conditions under which

kar 10 we have done this have either been one of the two things;
2 one is that both agencies have the authority to collect in-
3 formation.

4 MS. COX: They have the same authority about col-
5 lecting different data?

6 MR. SHISKIN: No. No. No. My point is that --
7 well, right, but let me come back to the case that I know of.

8 The OMB office of Emergency Planning, they intend-
9 ed to go out and collect, under mandatory planning, data that
10 were already collected by the Bureau of Census.

11 MS. COX: The same data?

12 MR. SHISKIN: The same data. And we said, "Don't
13 go do it." My immediate predecessor said that, and I agreed.
14 He said, " Don't do it." And he directed the director of the
15 census to transfer the information.

16 MS. COX: But he took the census -- he didn't get
17 any additional data?

18 MR. SHISKIN: No.

19 MS. COX: Then that is not linkage.

20 MS. GROMMERS: Pointing this up a little bit, I
21 think what you're referring to is a joint responsibility.
22 Once OMB has agreed that there be linkage, which if they didn't
23 do wouldn't be possible, then indeed there is another kind of
24 obligation that follows. Is that what you are saying?

25 MS. COX: The individual has given the Census

kar 11¹ Bureau -- under, one, confidentiality -- a use and they have
2 not been told that it is going to be used under another con-
3 dition for other information purposes.

4 MR. WAKSBERG: Well, using the term "census" is
5 probably an incorrect one because we have not turned any in-
6 formation over for purposes of linkages or anything else. But
7 you might refer to some other agencies and this is possible.

8 MS. COX: But now, wait a minute. He just got
9 through saying that they took your data, this special case.

10 MR. SHISKIN: We directed the census --

11 MS. COX: And to give him the data. They are using
12 it for a different purpose than you collected it for.

13 MR. WAKSBERG: I thought you had reference to link-
14 age, bringing two sets of data together.

15 MS. COX: Well, we have got off on another subject
16 because he made the example another one. Now, I don't know
17 how much the National Health Statistics uses data, census
18 data as a tie, but you use IRS.

19 MR. WAKSBERG: This is the same data. We use other
20 information.

21 MS. COX: Well, I made my question to mean where I
22 used IRS and the other have made confidential commitments which
23 is not needed, and now you are using it for a different pur-
24 pose.

25 MR. SHISKIN: I think that is a good point. Right.

kar 12 1 Right.

2 However, let me say this. It is a very difficult
3 issue and I hope it is the kind of reaction we need and that
4 we can get from you as to what is the sensitive issue, where
5 should we be careful?

6 What I can't say in ~~this~~ context, in this particu-
7 lar case, is the following. Some of you may know that we have
8 a business advisory council on federal reports. This is an
9 organization which tends to go throughout the whole business
10 community.

11 Now, we have discussed this, the use of tax returns
12 with them, and they support it. So I think we can say that
13 while we have not informed the individual, 2.2 million con-
14 cerns in the 1966 census that the tax returns were being used
15 in the censuses in view of direct reporting, we have discussed
16 it with official business representatives of those 2.2 million
17 people and, in general, they support it.

18 MS. COX: But I might be very unhappy to know that
19 the income tax reports go over to the census people and that's
20 what they use.

21 MS. GROMMERS: Would it be possible -- I'll just
22 ask the question for you, too, if you know -- that the con-
23 fidentiality comes by IRS and is not able to be backed up by
24 law, and for you to require -- if someone asks you if there
25 can be a linkage -- that this linkage be stated on a form, if

kar 13 1 as you control the forms?

2 MR. SHISKIN: Well, let me tell you about a recent
3 survey that I had a direct role in. Joe knows a great deal
4 about it, too.

5 Under our authority, we directed the Bureau of Vital
6 Statistics two years ago to make a contract with the Census
7 Bureau, for the Census Bureau to collect the data under the
8 Consumer Expenditure Survey. This was no small thing.

9 The Consumer Expenditure Survey is the biggest
10 survey in federal statistics outside the fixed census or the
11 population census and it is a very major step. And I might
12 say that everybody involved objected to it, both the Census
13 Bureau and the IRS.

14 Finally, they both reluctantly agreed, up to at
15 least a few weeks ago, and I don't think there would be lesser
16 evidence of it now, although they are happy with the quality
17 of the responses, as we thought in the first place, because we
18 thought the Census Bureau did the job cheaper.

19 MS. GROMMERS: To answer my question, would you be
20 able to -- whether you want to is a different matter -- would
21 you be able to require that this be put on the form?

22 MR. SHISKIN: I don't know exactly what I did or
23 what Dr. Brown did, the director of the census did or others
24 did, but what happened as part of this program is that Dr.
25 Brown, under his signature, wrote a letter to everybody in

kar 14 1 this probability sample of addresses and, he told me he ex-
2 plained to them in a separate letter, he told them, you see,
3 that the data would be collected by the Bureau of the Census
4 for the Bureau of Labor Statistics under the authority of the
5 Bureau of Labor Statistics law, and that these data would be
6 held strictly confidential and seen only by the Bureau of
7 Census and BLS employees.

8 Now, he wrote them a special letter and made that
9 clear.

10 Now, there are also statements on the ~~form~~ to that
11 effect, but I don't remember that. But I do remember very
12 clearly that Dr. Brown's letter.

13 So in this case, we did exactly what you suggest,
14 and I think it is a very wise factor.

15 MS. GROMMERS: Could you put it on the form? Could
16 you require it be on the form?

17 MR. SHISKIN: I think it says so on the form. I
18 don't remember. I don't have the form with me, but I think it
19 says so, I mean, in general.

20 MS. GROMMERS: In general.

21 MR. SHISKIN: Oh, we could certainly require it
22 because nobody could send out a form unless it has ten or more
23 numbers, and I think we do. I think we have the form. Do you
24 have it?

25 MR. WAKSBERG: I believe so.

end
10

kar 1 1 MR. SHISKIN: I believe it is on the form, but it
2 is crystal clear that in addition to the form itself -- by
3 the way, in this form, the respondent doesn't see the form.
4 He doesn't see it because the enumerator has the form.

5 So to get around that, we had a letter mailed,
6 signed by the director of the census explaining that to him.
7 By the way, it is a very interesting situation there because
8 as we anticipated, and I think the census people shared our
9 optimism, they were reluctant that they got the job. The re-
10 sponse was very, very good, certainly responsive than what the
11 BLS got on 1960.

12 MS. GROMMERS: You are certainly giving us some ex-
13 cellent ideas on what kind of advice we might be able to give
14 you.

15 Let me go on to just get on the floor for the record
16 the questions of these other four gentlemen and we hope very
17 much you are going to be coming back and talking to us, too.

18 Mr. Siemiller.

19 MR. SIEMILLER: I will pass.

20 MS. GROMMERS: Senor Anglero.

21 MR. ANGLERO: Well, I've got just a couple of simple
22 questions. As you mentioned before, you were in support, in
23 favor of the establishment of a central statistical agency.

24 MR. SHISKIN: Right.

25 MR. ANGLERO: Would you hold the same view if we

kar 2 1 talked about a statistical library and such as that instead of
2 a central federal agency, which could be a state or local
3 level?

4 MR. SHISKIN: Well, I really don't understand the
5 question. What do you mean by "library"?

6 MR. ANGLERO: Well, a place where all the statis-
7 tics could be governed, not having an agency to collect all
8 information but just to be available.

9 MS. GROMMERS: Is what you are referring to a
10 depository of records?

11 MR. SHISKIN: Individual records?

12 MR. ANGLERO: No. Statistical.

13 MR. SHISKIN: You mean books or tables?

14 MR. ANGLERO: All the information that could be
15 available to the public, instead of having it in different
16 agencies, to have it in one common place.

17 MR. SHISKIN: Let me make sure I understand. Let
18 me say it this way.

19 If you talking about bringing together statistical
20 tables prepared by many different agencies, certainly, I would
21 support that. I wouldn't oppose it. It depends on whether
22 it is useful, but I would find that I have no objection if it
23 is obvious it is a good thing to do. But if you talk about
24 bringing together individual records, I am opposed to it.

25 MR. ANGLERO: On statistical information?

kar 3

1 MR. SHISKIN: Why should I object to that?

2 MR. ANGLERO: Okay.

3 MR. SIEMILLER: Operated by the Congress.

4 MR. ANGLERO: On the other hand, would you assist
5 us about the need to collect or gather or accumulate personal
6 information on a central federal level?

7 MS. GROMMERS: How important do you think that
8 would be? Would that be a good idea?

9 MR. SHISKIN: To do what now? I don't understand.

10 MS. COX: Personal data?

11 MR. ANGLERO: To have -- I don't think I exactly
12 put it as you did. Let us put it this way.

13 We know that different agencies, even programs in
14 the same program, gather in personal information and keep it at
15 just the collector's and reporting sublevel. But some other
16 agencies do collect this information, personal information
17 and bring it to a level.

18 MS. GROMMERS: For example, a state's statistical
19 level?

20 MR. ANGLERO: Well, I can say state's vocational,
21 which is one I know. I can quote some others and also social
22 security. Okay? I'm just asking in terms of the need to do
23 it that way, to have it at a central level, this personal
24 data, personalized data.

25 MR. SHISKIN: Why should -- let me see if I can

kar 4 1 understand your question.

2 Why should the Social Security Administration, for
3 example, find it necessary to bring all the social security
4 data in one place or can they be centralized?

5 MS. GROMMERS: Do you think it is necessary? Is
6 there any reason for it?

7 MR. ANGLERO: Yes. You see?

8 MR. SHISKIN: Well, I don't know. I think you
9 would have -- I would have to look at each program separately
10 and make a judgment on it, and I would be reluctant to answer
11 that question.

12 MS. GROMMERS: Do you want to give us an example
13 of what you want?

14 MR. SHISKIN: I think I can understand the general
15 principle, which is the following. We faced this issue a
16 little more than a year ago because we instituted at that
17 time a major reorganization of federal statistics and our
18 reorganization plan provides for the establishment of six to
19 eight statistical centers, not one. So there would be six
20 or eight separate statistical centers.

21 So what I am saying is that we are opposed to a
22 large-scale single central data system and I guess that is all
23 I am willing to say. I do not want to deal with particular
24 programs because I don't know enough about them.

25 MS. GROMMERS: Senor Anglero, if I could help you,

kar 5 1 were you thinking of having one, why the data could not be
2 brought centrally and not to have them all locally in --

3 MR. ANGLERO: This is the data, all your data would
4 be collected and to have them considered any place at a cen-
5 tral level, in Baltimore or Fredericksburg.

6 MR. SHISKIN: Yes.

7 MS. GROMMERS: We are wondering what the advantage
8 would be in OMB, what they would see in this.

9 MR. SHISKIN: Madam Chairman, I am reluctant to
10 answer questions on particular programs. I don't know. I
11 would have to study a certain program.

12 I could only give you a principle, as a principle
13 opposed to bringing together large amounts of individual data.

14 MS. GROMMERS: We could perhaps refine that for
15 you and draw that out at another time.

16 Mr. Impara.

17 MR. IMPARA: Very briefly, to follow up on Ms. Cox's
18 question and Mr. Davey's question, and let me give it in terms
19 of an example, we heard Monday from a division of the National
20 Institutes of Health, Safety and Health, and they are collect-
21 ing data implementing an act for the Department of the Interior
22 relative to certain mine safety. It is conceivable that they
23 would provide certain data to the Department of the Interior.

24 As I understand it, the data that they are collect-
25 ing on medical histories is confidential under the rule of the

kar 6 1 Information Act under the personal information exclusion.

2 MR. SHISKIN: It is confidential.

3 MR. IMPARA: Its confidentiality is maintained be-
4 cause of the exclusion of medical information in the Freedom
5 of Information Act.

6 I guess my question is: Does the exclusion, if
7 they qualify for this exclusion under the Freedom of Informa-
8 tion Act as to making this information public, does that ex-
9 clusion go with the data or does it go with the agency respons-
10 ible for collecting the data?

11 MR. SHISKIN: Gee, I don't know the answer to that.
12 Do you, Joe?

13 MR. WAKSBERG: I don't know.

14 MR. IMPARA: Another example, if the Bureau of
15 Census data were to, under some circumstances, provide infor-
16 mation to another agency, whether the other agency had the
17 same kind of legal framework for confidentiality as the Bureau
18 of Census does, is the agency under restriction?

19 MS. COX: Or the individuals.

20 MR. IMPARA: Or the individuals or the --

21 MS. COX: Company.

22 MR. IMPARA: Are the data confidential regardless
23 of where they are housed or by whom, if under their original
24 collection they are deemed confidential?

25 MR. SHISKIN: I think it is the law that governs it

kar 7 1 not the data, because if you have confidentiality -- the Census
2 have a confidentiality law, and now, under the 1970 census,
3 they collected certain data about housing and individual
4 characteristics, and the decision was made that if it is appro-
5 priate to collect those data for the census, it is the law
6 which gives those data a confidentiality.

7 MR. WAKSBERG: Maybe an example of that or some
8 kind of application might help on that.

9 Occasionally in some of our programs, we feel it is
10 useful to have people in other agencies look at it as, maybe,
11 a joint program. Maybe they have some expertise that we want
12 them to look at it for.

13 The way this is done is to bring the people from the
14 agency and swear them in as employees of the Census Bureau,
15 as special agents so that they can be bound by the law which
16 says that the Census Bureau -- they are bound by the same law
17 as we are, and if they reveal that information, they are subject
18 to the same jail penalties as any other Census Bureau employee.

19 MR. IMPARA: If they fail to take that caution.

20 MR. WAKSBERG: They are breaking the law.

21 MR. IMPARA: Okay. Assume that there is some over-
22 sight where your law wasn't so straight. Let us translate it
23 to some agencies, some HEW agencies and they either brought
24 someone in or took their data to someone else and they perused
25 the data or held on to the data for some period of time. Does

kar 8 1 the law that covered the collection of data go with the data
2 to the other agency, or does the law only cover the data
3 while in these collecting agencies?

4 MR. WAKSBERG: I suppose you would have to look at
5 each one separately. The census law says no employee of the
6 Census Bureau -- it doesn't refer to the data. I says, no
7 employee of the Census Bureau shall reveal any of this or per-
8 mit any of this to be published in any form, and it relates
9 to penalties to employees of the Census Bureau.

10 MS. GROMMERS: Mr. Martin.

11 MR. MARTIN: I think I can clarify the point.

12 The Publication Information Act mandates the dis-
13 closure of information except in several specified cases where
14 there is a discretionary right not to disclose, so the exemptio
15 applies to the character of the information.

16 If an agency collected information which it had
17 discretion not to make public under the Freedom of Public
18 Information Act and transferred that data to another agency,
19 that agency vis-a-vis the Public Information Act would have
20 the same discretion not to disclose it.

21 If the transferring agencies imposed on the receiving
22 agency an obligation as a condition of the term of transfer to
23 exercise the discretion in the same manner, then the exception,
24 in effect, would follow the data. But unless it did that, it
25 is conceivable that the receiving agency could, if it chose

kar 9 1 under whatever pressures to, exercise its discretion not to
2 make it public differently.

3 MR. IMPARA: Thank you.

4 MR. SIEMILLER: Or to make it public.

5 MR. MARTIN: Yes.

6 MS. GROMMERS: Professor Allen.

7 MR. ALLEN: You have indicated the usefulness of
8 the administrative use of data and the transfer of some longer
9 limit conditions grown from one agency to another and there
10 has been some discussion of the confidentiality implications
11 of doing that, and I would like to make it a little more an
12 open-ended question to what extent the confidentiality con-
13 siderations are paramount to the extent that you don't do that
14 even more. That is, what are the implications for privacy
15 and confidentiality that you are aware of that limits your de-
16 cision to do that even more than is already done?

17 MR. SHISKIN: Well, my view on that is as follows.
18 I think now, in here, as I kept saying, we want your remarks,
19 your advice.

20 You asked me a question so I will answer it. My
21 view is that respondents object to the use of administrative
22 data for other administrative or regulatory uses. That is a
23 principle we sort of observe.

24 That is, if data are collected for one industry
25 purpose or like taxes, we think we would not agree to their

kar 10¹ use for another administrative purpose or for regulatory pur-
2 poses. But we would support their use for statistical pur-
3 poses under conditions that are of confidentiality.

4 So I would say that almost everywhere we see ad-
5 ministrative data available that could be used for statistical
6 purposes where the data are published as statistical totals,
7 et cetera, et cetera, we could encourage that; Medicare re-
8 cords, school enrollment information. There is a child care
9 operation. We would like to get at that so we would encourage
10 that for statistical purposes. We would oppose it for regula-
11 tory or other administrative purposes.

12 Is that responsive to your question?

13 MR. ALLEN: Yes, I guess. It says for statistical
14 purposes. There are no implications for confidentiality as
15 you perceive it, though?

16 MR. SHISKIN: Well, I have to keep saying that when
17 the data are transferred in such a way, that their confiden-
18 tiality is guaranteed. Now, I must say that I am troubled by
19 Dr. Cox's response about not informing the respondents.

20 MS. COX: Plus the fact that when you begin to link
21 data, you reveal more and you are going to identify individuals

22 MR. SHISKIN: No. How long will this committee be
23 in existence?

24 MS. GROMMERS: Our charter at the moment extends
25 through June 31. May I ask why you were wondering?

kar 11 1 MR. SHISKIN: I would hope that we could meet
2 again, frankly, because this is a great opportunity for me,
3 and at the next meeting we would be discussing in somewhat
4 greater depths when there are other people here some of the
5 questions you asked.

6 I think it is a very important question from Dr.
7 Cox, just a question about practicality; what should we do?
8 Write letters to 2.2 million respondents?

9 MR. WAKSBERG: How about the 72 million families
10 on the 1040s?

11 MR. SHISKIN: Yes. What is our obligation? Do we
12 write them? Is the way we are doing it okay? Do we go to the
13 business community and talk to their representatives and tell
14 them this is a big problem and we'd like to discuss it?

15 Also, Madam Chairman, I really hope we can get to-
16 gether before you are finished and you can sort of respond to
17 these ideas and we can get your reaction. I would like to know
18 what your reaction is on this issue that Joe and I raised.

19 Is a probability sample of addresses confidential?
20 Or should we try to get the director of the census to transfer
21 such a probability sample of addresses, let's say, from Census
22 to National Center for Health Statistics? We would like your
23 reaction to these questions.

24 Is our program of maximizing the use of administra-
25 tor records not only for business returns, which we are doing

kar 12 1 on a very large scale, but hopefully as a proxy for mid-decade
2 census? Is this a good idea?

3 So we would like your reaction.

4 MS. GROMMERS: Dr. Shiskin, we are very grateful
5 for the opportunity to do this. As we are interviewing various
6 committees, we are coming to some conclusions about this.

7 But based on some very interesting information that
8 we are covering and uncovering as we are interviewing a large
9 number of different kinds of agencies with the same kinds of
10 questions, we may very well be able to have some actual data
11 to back up what we might suggest to you.

12 MS. COX: We are not quite done.

13 MR. SHISKIN: You will eventually have the report,
14 I presume?

15 MS. GROMMERS: Well, we hope we will interact with
16 you long before that, knowing that that is going to be so long,
17 but we would like to talk to you sooner.

18 May I suggest that we stand up and stretch here in
19 the room for five minutes, and I will call you back to order.
20 If you could, Dr. Waksberg, we would like to have you stay,
21 if you could, and then we will go on to the other presentations

22 (Brief recess.)

23 MS. GROMMERS: This is off the record.

24 (Discussion off the record.)

25 MS. GROMMERS: We apparently have been generating

kar 13¹

some enthusiasm here for committee interaction.

2

3

4

5

6

7

8

9

10

11

12

13

14

15

16

17

18

19

20

21

22

23

24

25

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 passover 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. WAKSBERG: 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-

kar 141 formation from some other kind of record, collating the two
2 and producing whatever kind of statistics that can be done.

3 Well, it turns out that as a practical issue, al-
4 though this would be possible, which you wouldn't if one had
5 an infinite amount of money, but with the Government budgets
6 being what they are, even with hundreds of millions of dollars,
7 this almost impractical.

8 The only practical way of bringing data together,
9 large-scale sets of data together from various sources is if
10 there are some reasonably unique numbering systems whether it
11 is social security number or some other numbering systems,
12 under almost any other circumstances. The only things that
13 can be done are relatively small-scale jobs, things with may-
14 be a couple thousand people, ten thousand, two thousand, five
15 thousand.

16 We have done sample studies where we have tried to
17 bring bits of information together of various types but this
18 is just not feasible on a large scale unless you get involved
19 with computer matching up ratios in which case you need iden-
20 tical identification first. Well, there was pressure, I might
21 say. There was pressure --

22 MS. GROMMERS: Excuse me. May we just challenge
23 you on that. We don't believe you do need them. Could you
24 just say why you need identical ones and not a program that
25 will link?

kar 15

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.

Assoc Federal Reporters, Inc.

6933
pad 12
ph 1

1 MR. WAKSBERG: As a result, where we do not have
2 these unique identifiers, we ~~tend~~ to -- well, the only link-
3 age jobs that I can recall in the census of this type are
4 those that are done on relatively small scales to investigate
5 particular statistical matters.

6 We have compared some information from Medicare
7 records with the census to measure coverage of the older
8 persons of the United States, to measure age reporting but
9 these are based on the samples of a few thousand cases where
10 we actually look and try to compare names and addresses.

11 The large scale jobs to be practical require
12 numbers, and in the census, we just don't have them.

13 We made a decision before the 1970 census that
14 we would not ask for social security numbers which is at
15 present really the only universal method for doing this in
16 the United States.

17 We did not ask for that because our feeling was
18 that the kinds of uses we could visualize where we would
19 want to link large scale records of census to other things
20 just weren't great enough to warrant the kind of problems,
21 public relations, problems of ethics and morality of getting
22 social security numbers and making this available.

23 In fact, if you look at what we put on tape, on
24 our magnetic tape in the population census, for example, not
25 only don't we have social security numbers but we don't have

1 names, either.

ph 2

2 From an automated basis, it would be impossible
3 to do anything with our computer tapes.

4 Now, this does not hold true in the case of some
5 of our economic results for information, if a company is so
6 unique that in order to be able to deal with it, to be able
7 to produce statistics, that you do need information on
8 names. But in our population, in our demographic information
9 where we get into data on persons, on households, we do not
10 put any kind of identifiers of this sort on tape.

11 Now, we do use information from other agencies
12 for various special purposes and then we mentioned a few of
13 those cause some of the kinds of relations that are kind of
14 various and that Dr. Cox related to as to notifying people
15 of information, and there are some troublesome issues.

16 Let me mention one piece of work that we are
17 doing right now. There are many pressures on the government
18 as a whole, government statistical system to provide updated
19 population counts for each city, each county in the United
20 States.

21 Billions of dollars are transferred from the
22 federal government to localities from the states to local-
23 ities, much of it being on the basis of population counts.
24 In the present system, these are gotten only once a year.

25 Proposals had been made for a mid-decade census

ph 3

1 to update that, and as Mr. Shiskin mentioned earlier, the
2 costs of those things are so large that they seem inadvisable.

3 So we have been examining other ways of getting
4 reasonably good recordings of population counts, and the one
5 that appears most promising is as follows.

6 To start up with a simple technique, starting off
7 with Washington, Montgomery County, we start off with the
8 1967 figure for population, and you add to that information
9 that has been tabulated from birth records, from vital stat-
10 istics -- and these are not individual reports but simply
11 the number of births in this city -- you subtract the number
12 of deaths and this is accounting for everything except interim
13 migration of people leaving the cities, moving some place and
14 then coming back.

15 So we have been exploring the possibility of using
16 IRS data to give us estimates of movements. And the method
17 of using IRS that appears most promising is to take two
18 periods of time, let us say that we suppose that we start
19 off with 1970 IRS returns and also take 1972 and get the
20 full set of returns; this does not include the income data
21 but simply the fact that people who have filed returns, claim-
22 ing four exemptions, let us say, which indicates the number
23 of persons in the household who have filed a return at such
24 and such an address, well, we collate the returns for the
25 two years and the collation is completely mechanical and

Don Federal Reporting, Inc.

1 based on social security numbers.

ph 4

2 This is the only way it is practical.

3 At the point in collation, you look for people
4 who have changed addresses during the two periods and you
5 see to what extent those addresses reflect movement, let us
6 say, from ~~Washington~~, out of Washington or from outside of
7 Washington to inside Washington, if you wanted to do that.

8 It turns out that this technique, at present, for
9 examination in the case is that this is a very encouraging
10 technique and may provide us with much better estimates for
11 the population at any point in time.

12 And it may enable us to actually provide annually
13 updating of the population figures with a reasonably good
14 reliability.

15 But to do this requires using 70 million records
16 each year.

17 The advantages are the providing of more accurate
18 figures for purposes which have a very tangible and definite
19 use. In effect, the better distribution of billions of
20 dollars in funds, the more equitable distribution.

21 The only disadvantage is that we are using IRS
22 data for a somewhat different purpose than it was collected.

23 Now, the information that we get from IRS, we
24 hold it as confidential under the same kind of rules, as we
25 hold any other kind of data. The notion of feeling we have

-h 5

1 to notify all 70 million households of the fact that we are
2 doing this is sort of, my personal feeling, sort of a
3 sobering thought.

4 And I guess my reaction is I see no reason why
5 this couldn't be put in the general distribution in terms of
6 press releases, information and publications and so on, and
7 I would like to propose this for some selected uses for
8 the committee to consider this as an alternative of these
9 general kinds of notifications, rather than specific notifi-
10 cations on the household by household basis.

11 MS. GROMMERS: Mr. Waksberg, I am afraid it is
12 7 minutes. now. Would you like one or two closing remarks?
13 That would finish that first pass that we could take.

14 MR. WAKSBERG: Well, let me just close my remarks
15 by mentioning other kinds of uses.

16 The more common use that we are making of anything
17 that can be considered data linkage is in our economic stat-
18 istics. Mr. Shiskin referred to that earlier, where an ef-
19 fective mailing list for many of our economic studies are
20 based on lists, either Internal Revenue Service lists or
21 social security lists.

22 There are some occassional other sources that
23 come in but these are the main ones.

24 About the only information that is used there
25 is the name, the address, the kind of business it is and the

ph 6

1 measure of the level of activity of the company. These tend
2 to be sort of the major kinds of uses of data from other
3 records that we have.

4 MS. GROMMERS: Thank you very much.

5 I think we will just go for our second speaker.

6 Mr. Schor.

7 MR. SCHOR: I will try to --

8 MS. GROMMERS: Will you introduce yourself just
9 very briefly, first.

10 MR. SCHOR: I am Sigmund Schor, director of the
11 National Center for Social Statistics. This center is the
12 statistical arm of the Social and Rehabilitation Service and
13 as such, its program is a reflection of a response to the
14 various program needs of the Social and Rehabilitation
15 Service.

16 Just to give you a quickie half-minute over-
17 view, the Social and Rehabilitation Service is responsible
18 for the welfare program in the United States on Medicaid,
19 program of social services, vocational rehabilitation ser-
20 vices and the other program which is the juvenile delinquent
21 program, the program of aging, and, last but by no means
22 least, the Cuban Refugee program.

23 So you can see this is a varied program and re-
24 quires quite a bit of statistics.

25 Now, we collect our data on the basis of the same

ph 7

1 legislation; our authorization comes from the legislation
2 which authoriaes the existence, the establishment and the
3 existence of the Social and Rehabilitation Service, so
4 that the Secretary may decree, he may collect any kinds of
5 information he so wishes for the proper administration of
6 the program.

7 And in determining what is a good statistical
8 program in terms of what are the needs, we do try to the
9 extent possible to communicate with the states on the various
10 uses of our statistics which run from the Congress, of course,
11 the Office of Management and Budget, and various other
12 parts of government, not to mention of course all the other
13 sister agencies.

14 The data we collect are about people, recipients
15 of welfare people who have been rehabilitated. The source
16 of our data are the state agencies themselves, and the
17 kinds of data we collect are primarily operating data,
18 merely, how many? what kind? what do you do for them? what
19 characteristics? what services have they received? and this
20 type of thing.

21 Now, I am trying to cut this down to save time
22 here.

23 We recieve our data primarily in three ways.
24 One is we collect data in some brieif form from these state
25 agencies. Incidentally, state agencies may be any kind of

ph 8

1 agency that has responsibility at the state level for any
2 of our programs. It might be a health department, department
3 of human resources, of vocational rehabilitation agency,
4 what have you -- quite a variety of agencies we deal with,
5 which is one of our very many problems of course in collectin
6 data.

7 But one way of collecting it primarily is to
8 collect from the state a summary at the state level, leaving
9 it to the state to worry about the geography below the
10 state level.

11 We collect state data in a prescribed form which
12 are actually statistical tables.

13 How the state produces this is the state's affair
14 unfortunately, and if you keep in mind that approximately
15 half the states in the United States have a county welfare
16 program, we are dealing with quite a number of reporting
17 agencies.

18 In any case, we get these data in summary form
19 and I will just pass this one by and say I don't even see
20 any problem in that area about disclosure or confidentiality.

21 We are doing it with a very large area, essential
22 the state. As a matter of fact, the only exception we make
23 to that is that we do get some limited data, number of recip-
24 ients I believe, and expenditures at the county level.

25 But beyond that, these are state tables. I don't

ph 9

1 see any problem in disclosure, confidentiality in our area.

2 Now, forgive me. I am trying to breeze through
3 this.

4 MS. GROMMERS: We appreciate this.

5 MR. SCHOR: Another way in which we collect
6 data is, of course, the survey technique where we go out
7 and we design a sample and we send it out to the states
8 and we ask the states to complete our questionnaires about
9 a survey of recipients.

10 Now, it is a sample survey, and for example,
11 if we do a survey of the program called Aid to Family Depen-
12 dent Children, we would probably take a one percent sample,
13 roughly, and deal with about 25,000 cases which might cover
14 some 75,000 to 100,000 people.

15 Here, too, we make very gross tabulations at the
16 national level, not very finely detailed. Sometimes, we
17 never have time to do this. Other resources could do
18 this, but they are state, national tabulations, and we provide
19 state tabulations for only a few with large enough to provide
20 reasonably good state estimates.

21 I hope you can hear me back there.

22 And as I would say, here, too, I do not believe
23 we have any kind of a disclosure problem because the data
24 are, of course, a sample. They are for large geographic
25 areas.

ph 10

1 I don't see any problem in getting -- wrong data
2 getting into the wrong hands.

3 When we tape these data and put them on to com-
4 puter tapes, more personal identification is eliminated.
5 We collect personal identification only for purposes to be
6 able to follow back with the states where we have a lack of
7 information where they didn't supply the data and we suspect
8 the quality that they did in this and so on, but once it is
9 on tape we wipe it all out and produce our tabulations.

10 I see no problem there. Maybe we can come back
11 to where I see the problems.

12 The third way of collecting data where we have
13 the vocational rehabilitation, we get not a sample but we
14 get a complete record of every single disclosure made during
15 the year. However, I am going to skip this one by completely
16 because I know that Monday morning you had a two hour ses-
17 sion with one of my staff memners, Lesley Grier, who spent
18 two hours on that session.

19 I think he worked that one out. I will pass that
20 one.

21 Where are the problems? I see they are in
22 Washington. I don't see any problems in terms of disclosure
23 or confidentiality.

24 Now, one of the problems arises where, let us
25 say, you have one of the smaller agencies and when an organ-

Am Federal Reporter, Inc.

oh 11

v

1 ization has its own computer set up, its own programmers,
2 its own system and so on, it can sort of keep an eye on its
3 data to see in whose hands the datum gets, who has access to
4 the datum -- by "datum", I am talking about the original
5 question which had come in and which aims to accuracy, being
6 very, very specific about people.

7 However, we find that we have to use it because
8 we don't have any of these resources and there are a lot
9 of other places in the department that are small like this
10 that don't have their own resources.

11 They are obliged to go to a central processing
12 organization in another department called DMC, for example,
13 in our own Department of HEW.

14 What you find when you send that over is the
15 obvious; they don't have the resources either, and the next
16 thing that comes up is a dirty word called "contractor."

17 It is a dirty word because we can't control this.
18 We have no way of keeping control or a handle on it as to who
19 has access to the data. I consider this a very major prob-
20 lem.

21 We, locally, try to make an inspection. Maybe
22 it is a term, a funny term. We can't keep up with it.
23 If it is local, we put our heads in and see what they are
24 doing, lay the data all over the floor and so on.

25

Also Federal Reporters, Inc.

ph 12

Assoc. Federal Reporters, Inc.

1 But even so, you have it written into contracts:
2 there are certain prescribed formulae, you will maintain
3 confidentiality, and so on.

4 There is absolutely no formal audit made. There
5 is a potential. I would not say it has happened, but I can
6 see a very good potential for somebody, some contractor
7 perhaps faced with financial problems using these and making
8 up mailing lists and selling mailing lists to some poor
9 people.

10 I don't see anything to stop them. But of course
11 there is a law that says it is confidential.

12 The second area where I see problems is in our
13 states. These are the suppliers of our data.

14 All our regulations prescribed that the state
15 plan, under which the states operate, have a clause of
16 confidentiality. It is very impressive, it says so. It
17 is written in the Federal Register.

18 I saw on the roster where there are probably
19 two state assemblymen, senators, state legislators,
20 I don't doubt the ability of either one of these calling,
21 picking up a telephone and calling the county welfare and
22 finding out about anyone he wants to find out on, on the
23 rolls.

24 Obviously it is a political program, and I am
25 sure that this kind of thing is potentially possible.

h 13

1 Even when you go beyond this, the states, there
2 are 54 jurisdictions that we deal with directly and 54 levels
3 of sophistication and computer equipment, and how they handle
4 them and at one extreme, you will undoubtedly find some
5 states that have built in safeguards on data.

6 I am sure there a few in number.

7 On the other extreme, you have states that deal
8 with manual systems and they have data on 3 by 5 cards with
9 lines all over the place, and even there, when you have auto-
10 mated systems, you learn about the protection, the integrity
11 of the data.

12 In many states, the agency with whom we deal, he
13 the agency which is the source of this informatin, and the
14 training has to do with some other central place, which is
15 just the situation mentioned a while ago, was to the central
16 location and to the processing of it and they would say,
17 "process it for me because I am required to report those
18 data to somebody in Washington." What happens?

19 Again, they may be overloaded and they go to
20 a private contractor. So I see information about people, I
21 mean real live people, names, addresses, right on down the
22 line, being circulated and in the hands of people where we
23 have, or what I consider, darned good protection.

24 I repeat. I don't think we have very much
25 problem here at the Washington level. We do take reasonable

Also Federal Reporters, Inc.

ph 14

Ac Federal Reporters, Inc.

1 care and precautions.

2 I am reasonably sure of this.

3 What happens out there in the world is the states
4 and what entity within the state has a part to play in the
5 manipulation of these data, and in the world of private in-
6 dustry I think there is a potential problem there on con-
7 fidentiality and disclosure information.

8 MS. GROMMERS: I think that is a very beautiful
9 presentation. At this point, I presume you are speaking
10 about a budgetary problem with your short staff?

11 MR. WAKSBERG: It is probably. I don't think it
12 is a budgetary problem. I think it is a political problem.

13 I would like to point out that we are taking
14 steps to help states, to provide guidance, counsel on hard-
15 ware, soft ware, methods of processing data; in other words,
16 of trying to bring some order of standardization into this
17 whole thing, and once you reach some acceptable level of
18 standardization, I would consider the next step would be
19 to build in very specific safeguards.

20 How do you protect them? Are they safe? I don't
21 know. By swearing in people who may have access to it?
22 Maybe it takes law. Maybe it takes additional law the way
23 Mr. Shiskin was indicating. I don't know. I think that
24 eventually can be licked.

25 The other one, the contractors is a matter of --

ph 15

1 it is a budgetary problem, obviously, if you don't have staff
2 where you hire people to do it for you.

3 There truly is no alternative. These people
4 should be on the government payroll.

5 MS. GROMMERS: I'd like to come back to that
6 point and I am sure the other committee members will do it
7 for me. Maybe we ought to go on to Mr. Carroll for the
8 moment.

end 12

Academy Federal Reporters, Inc.

9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25

Macias
6933
1
end.

1 MR. CARROLL: I am Jack Carroll, the assistant
2 commissioner for research and statistics in the Social
3 Security Administration and our office is the research arm
4 for the old age survivors disabilities health programs, just
5 as Sig mentioned that his organization is prepared for SRS,
6 there has been an office of this type in Social Security from
7 the beginning of the program.

8 Fortunate for the program, it was written into
9 legislation and we continue to do a lot of research that you
10 might expect may be necessary in this area, make available
11 statistics for this. We do not collect statistics.

12 I think it is an important point to make, that
13 most of the information to be used is collected in the
14 operations portion of the Social Security Administration in
15 doing their functions, collecting information about the wages
16 of the people who they cover, and they do that from about five
17 million employers and indirectly then, through the employers,
18 get the information about the wages of something like 90
19 million workers each year.

20 What we do in OAS, we have five divisions. One
21 of these divisions is specifically oriented toward accessing
22 this information from the operating records and, of course,
23 the thing that interests me most is that I am getting those
24 for research projects in which we are interested and for
25 general information and statistics which we feel need to be

Macias
2

1 made available to a wider unity. There are also a good many
2 administrative uses of these statistics, and I take it that
3 is not your major interest.

4 We publish a lot of this information because it
5 is generally useful to have it available to a very broad
6 community and the division of statistics in our office makes
7 available information, such publications for -- well, we
8 have an annual statistical bulletin that goes along with the
9 Social Security bulletin where we publish a great deal of
10 information on a monthly basis.

11 We also publish a number of annual reports on
12 special subject groups; for instance, farmers and farm
13 workers, household workers, state, local government
14 employees, farms, subsidiaries, self-employed doctors. Lots
15 of information with very specialized type.

16 We also make available to the Congress information
17 about beneficiaries amounts made and so on, on a state and
18 county basis, and we supply the Census with information for
19 the county business patterns.

20 Just recently, we began making another use of the
21 information to give people an idea of what the earnings
22 distributions are in the largest SMSA's in the country for
23 people, broken by race and sex.

24 As you can see then, there is a wealth of
25 information here, and our objective is to make it available

1 to a broad community, society, so it can be useful because we
2 never could hope to type it ourselves. So we try to make
3 use of it in analytical studies in which we are engaged.

4 I will say something quickly about the fact
5 that we also make the information available on tape, some
6 parts of this information. We, from very long back, had
7 taken a 1% sample of our records and in recent years we have
8 been willing to sell that, put it into a form where identifica-
9 tion has been stripped off and the information is useful
10 for statistical purposes. We are willing to provide quite
11 a bit of technical assistance in order to make it really
12 available to people.

13 I hate to get away from that. That is one of
14 my favorite subjects, but will go on to say that we also
15 realize we need to have information about the whole population
16 at least and not those that we just happen to reach. So we
17 have to do a whole series of surveys. And I say "we" do them.

18 Actually, we design surveys but we contract with
19 other agencies to collect the information; usually Census, and
20 when we do that--John Waksberg has pointed it out for us which
21 I don't have to repeat--we make an arrangement that the people
22 are sworn in as Census agents so there is assurance that there
23 is the same kind of confidentiality at the Census that is
24 guaranteed people.

25 In this way, we ran a First National Survey. The

1 agent ran a First National Survey of the disabled, and when
2 Medicare began, we realized we had to get information about
3 how the Medicare program was working as quickly as possible.
4 We have done that on a monthly sample basis, again working
5 with the Census.

6 Now, who decides what is to be done? I tried
7 to look over your questions. I didn't realize I would have
8 to answer them in seven minutes. Actually, as we proceeded,
9 I thought it would be more fun to ask the questions that
10 has been asked at this seminar.

11 This seminar is kind of good fun, actually. I
12 shar Julius' view on that.

13 The Commissioner ultimately is the man that
14 decides what we are going to do. But just as all commissioner
15 he takes advice from a lot of people. We depend a lot on
16 advisory groups and usually these advisory groups have come
17 from professional societies, from academic circles, from
18 other research organizations and give us some feel for what
19 they feel would be helpful.

20 For instance, before Medicare statistics were
21 put together, we had the advice of very distinguished groups
22 from outside the government.

23 As far as matching is concerned, I want to quickly
24 say that we do these surveys from outside by using census,
25 generally the census. Sometimes we want to enrich the
information though by linking it up with our own information.

Macias

1 If, for instance on the longitudinal study on the
2 retirement history, we can find out what the earnings of
3 these people are, which we can do from our own records, we
4 put that information together with the information that
5 they have given us. And then we have more information than,
6 as Doctor Cox has said before, maybe they realized, because
7 I don't believe we tell them that we are going to do that.

8 But on the other hand, we keep all the information
9 just as confidential as we had told them. All right.

10 I think it is an interesting question that was
11 raised earlier about what to do about that. I want to
12 mention something that many of you may know about, and that
13 is that outsiders are forever sending social security
14 numbers and wanting us to "give us some information" and
15 saying, "Golly. We don't know what to give them." If people
16 are willing to waive their rights and give permission for that,
17 we don't have much choice. We have to give that information.

18 We do not encourage that. In fact, we discourage
19 it in a way, by explaining to researchers some problems
20 related with that and try to get them instead to give us
21 social security numbers if they have them simply for statis-
22 tical tabulation feedback to them which is much, much better
23 a way of doing it. And from their point of view, as well, it
24 is a better way. We try to persuade them of that.

25 Now, as was suggested earlier, there are from

Macias

6

1 time to time efforts to link, cooperative efforts to link
2 other information with the census, things of those sorts.
3 Most of those are for methodological purposes and serve a
4 very useful purpose.

5 Again, as Joe was saying, it might be very
6 difficult to think and tell everyone that we are doing this
7 and I don't believe that we do, but take the case of their
8 trying to find out better information about people over 65.
9 You know, to get Medicare, to get social security, you have
10 to prove how old you are. I mean, you really do. That is a
11 very complicated process. And so our records about people
12 over 65 are better than just plain survey information.

13 What the Census wants to know is how much better,
14 how much different, you know. And therefore, we supply that
15 information to them on a cooperative basis so that they can
16 improve their methodology.

17 In order to get that information, incidentally,
18 even though the government is dealing with itself, the
19 Commissioner has to exercise his prerogative under what --
20 where did Julius go? -- what Julius said is not very tight
21 confidentiality. I thought we had a pretty tight one.

22 It is true, however, and this is what Julius had
23 in mind, of course, that under certain number of situations,
24 if the Commissioner and Secretary wish to do so on an ad hoc
25 basis, they can make an exception to the confidentiality

Macias

7

1 restriction and we did that in order to give the Census this
2 information. That is an illustration of when we do it.

3 As you can see, I could go on and on. But I
4 will adopt Doctor Cox's term and say "pass." Must have been
5 Ohio.

6 MS. GROMMERS: Thank you very much, Mr. Carroll.
7 We will appreciate your pass and hear from Mr. Simmons.

8 MR. SIMMONS: I am Walt Simmons, assistant
9 director for National Center for Health Statistics. Now,
10 our Center is not in the business of automated personal
11 data systems and, indeed, we have taken quite a bit of efforts
12 to stay out of any operational role in that field.

13 But, contrastingly, we do of course deal heavily
14 with information about individual persons and individual
15 business establishments and we are very much concerned
16 about questions of confidentiality, invasion of privacy,
17 Freedom of Information and all these related topics.

18 Our general position in these fields I think is
19 very similar to that which you spent a good bit of time this
20 afternoon hearing from Julius Shiskin and Joe Waksberg, that
21 we sometimes say in our Center that we are something of a
22 lineal descendant of the Census Bureau; at least in the
23 handling of data in those respects.

24 We do make a great deal of distinction, a very
25 sharp distinction between the use of data for statistical

lacias

9

1 purposes and the use of data where the individual unit can
2 be recognized and possibly used for purposes of administrative
3 uses or taxation or regulation inspection, any such kind of
4 activity of it, we are not engaged in any of the latter
5 kinds or types.

6 Now, we did have from your secretariat quite a
7 list of questions to which we might address ourselves. I
8 was impressed, if I may say so, with the insight and the
9 perception of underlying issues that was behind that set of
10 questions. I think there were about 53 of them. In the seven
11 minutes that we have, I am not going to deal with very many
12 of those. So I will take our Chairman's direction and simply
13 refer mostly to things that we might have talked about if we
14 had more time.

15 I will say that our Center is the principal
16 general-purpose collecting agency in the health field in the
17 government, and is so recognized as a part of the federal
18 statistical system which was referred to earlier.

19 We collect data through a great variety of
20 techniques and over quite a range of health topics. I think
21 we currently recognize some 17 different general mechanisms
22 for collecting data in such areas as the vital events
23 field: births, deaths, marriages, divorces. We used the
24 household interviewing. We take probability samples of
25 population and give physical examinations to these people.

1 We have inventories of facilities which provide
2 services in the health and allied fields. We have a system
3 of sampling of hospitals and discharges from those hospitals
4 and character of people in the hospitals.

5 We deal with long stay institutions, both one
6 hundred percent and samples. We cover staff. We cover
7 facilities. We cover the residents of such places. We have
8 a nutrition survey.

9 We have several kinds of what we call record
10 anchored surveys, following back surveys where the frame for
11 drawing the sample is such things as the vital events
12 certificates and we go back for additional information.

13 Then we have several other kinds of techniques.
14 Now, we are the largest health collecting unit in the
15 government but by no means the only one, not the only one even
16 in the department.

17 As a matter of fact, I think budget-wise, we have
18 about \$19 million of a budget currently. I think the rest of
19 the department has something in the neighborhood of \$30 million
20 in budget.

21 Our programs are distinguished especially by the
22 fact that they are national in scope. They are continuing in
23 character. They are general in purpose. They are baseline
24 background kinds of data.

25 We have quite extensive legal authorization both

Macias
19

1 in terms of latitude and in terms of direction for topics
2 which we should provide information. There is one other area
3 of legislative activity which I want to mention very briefly
4 and it came as a little bit of a surprise to me today.

5 This deals with the question of our -- the legal
6 basis for our handling of confidential matters. I was a
7 little surprised to find Julius Shiskin mentioning that only
8 the Census Bureau had an adequate law in this respect, and
9 we think our law is pretty strong in this respect.

10 We believe that it prohibits absolutely no
11 transfer of information to anybody outside our Center without
12 the consent of the person supplying the information. I will
13 talk to Julius some more about this.

14 On the question of program determination as to
15 who decides what we do, well, of course, in one sense, Congress
16 and the Executive branch of government generally do this and
17 our own organization, internally. But in particular, there
18 are I think four points that I might mention in this
19 connection.

20 There first exists a U. S. National Committee on
21 Vital Statistics which has been appointed by the former
22 Surgeon General and now by the Assistant Secretary for Health
23 and Scientific Affairs which is a public committee widely
24 representative of, generally speaking, the health of the
25 community of the country which is advisory to all of our

acias
12

1 activities. A second thing is a mail -- that's m-a-i-l --
2 panel of 150 advisers which we try to keep informed by a
3 series of outgoing communications from our office of what
4 events are taking place and what we expect we may be doing in
5 the future and inviting comments from these people and
6 suggestions and recommendations.

7 We get a very heavy flow back from our 150
8 panel members and we are pleased with this technique. It is
9 one of the most useful and valuable devices we have.

10 A third element is or was called a public health
11 conference on records and statistics. It is called a
12 conference but it is a thing that extends all the time,
13 exists bi -- meets bi-annually and, in between meetings, is
14 served mostly by derivative technical consultant panels which
15 are sort of subcommittees of the conference organization.

16 This is mostly people by universities and by state
17 and local personnel.

18 Finally, we have a formal annual internal program
19 review which consolidates all the information that comes
20 in from other sources, and our own organization that tries
21 to set up a program budget each year. We use publication,
22 printed publication as our primary method of distribution of
23 information. But we do have a policy of making available
24 magnetic tapes for elementary units in a form in which the
25 elementary unit cannot be identified as an individual person

1 or place.

2 I will leave with you a little pamphlet that
3 describes how we go about this. I think that my approximate
4 seven minutes is about up.

5 There are a good many -- as I say, I was impressed
6 by this list of topics on which we might comment. There are
7 a good many of them on which there are things that I might
8 like to say, and I would like to get some reaction from you.
9 But I guess in this first round, I will have to pass over most
10 of those, but I would close with one other kind of remark
11 which echoes in some respects, at least, what Mr. Schor said
12 a few moments ago.

13 Now, for us in the National Center for Health
14 Statistics, I think I can say that there are a few matters
15 that take more of the time and attention of our senior staff
16 than these questions that are under discussion here today.

17 Somebody raised the question a while ago of
18 confidentiality being paramount. Confidentiality and related
19 matters are certainly of very significant aspect in our
20 undertaking. There are new things happening every day.

21 Now, up to the present time, although it's been
22 sometimes fun and sometimes very difficult, I think we have
23 kept pretty well on top of this question. But our Center, as
24 I indicated, has mostly been engaged in national surveys and
25 has been federal and national in scope and we are now heading

1 into a period in which we will be a part -- in addition, a
2 part of a cooperative federal, state, local activity in the
3 health field. And here I have a good bit of uneasiness about
4 our ability to maintain the same kind of standards in this
5 field that we have in the past and the problems come in our
6 eyes in two directions primarily: one, even among the
7 statistical agencies, and if we restrict it just to states,
8 we will be talking about 50 semi-sovereign jurisdictions
9 instead of the one that we have to contend with at the
10 moment. On the other hand, and perhaps even more severe, is
11 the problem that at the local and state level, very often
12 the statistical organization and the operating activity and
13 inspection organization or regulatory body are very nearly
14 in the same organizational setup and it gets extremely
15 difficult to keep the wall between the statistical purposes
16 only and the operational uses in such an environment.

17 I think this constitutes one of the most serious
18 types of problem for the statistical people in this realm.

19 MS. GROMMERS: Thank you so much, Mr. Simmons,
20 and thank you also for the quick pass. We will introduce to
21 you Doctor Nisselson and then we will be able to have those
22 questions you have all been waiting for.

23 MR. NISSELSO: I am Harold Nisselson, Assistant
24 Director of Research for the National Center for Educational
25 Statistics which is the statistical center of the Office of

facias
15

1 Education.

2 What I would like to do is submit for the record
3 some material about ourselves and a statement and just talk
4 a little about some of the problems that we think we have
5 and try to get your help on them, try to answer the questions
6 that you may have.

7 First of all, we are probably unique in some
8 sense because the Department of Education, as it was
9 originally called, was founded in 1867 -- wasn't it? Yes. --
10 solely for the purpose, entirely for the purpose of collecting
11 statistics and facts about education in several states, you
12 know, the kind of language they had in those days.

13 After about 98 years, in 1965, this explosion of
14 federal activity and federal concern in education, which
15 constitutionally is a local concern, took place. And with that
16 came the explosion on information demand and in response to
17 outside advice, the Commissioner established the National
18 Center for Educational Statistics in 1965.

19 So it really is a very new Center and things have
20 just been going from bad to worse. It's kind of like living
21 in a high-temp cannonball reaction; lot of heat, lot of
22 things happening very fast. And I think we not had the time
23 to develop tools nor the traditional tools that other fields
24 have had, and I think that we are hurt a lot more because of
25 that even though our intentions are good.

acias
16

1 We started out originally with a great deal of
2 concern particularly because of the local orientation of
3 education, with education as an industry, if I might call it
4 that. And it wasn't until the compensatory legislation that
5 the federal government really got interested in things like
6 process, what was going on, what were you doing to the kids? --
7 which created for us the kinds of problems of information
8 about individual teachers, individual students which created
9 the very difficult problems of confidentiality.

10 I might illustrate the changing attitude of people
11 by telling you about a Ph.D. candidate at Columbia a couple
12 of years ago who got to wondering if education is now failing
13 children. It is not educating the children. At what point
14 did it start failing them? There was some time when it was
15 serving them.

16 So he started moving around in early records in
17 New York State and he was able to find something like in
18 Baltimore, Syracuse. They tested all the cases and so on.
19 And he found that in the higher Victorian age where schools
20 were in well-disciplined shape and kids were shot within 300
21 yards, they were failing the same kids.

22 Now, it is just that we are now getting impatient
23 with them. We are not willing to have that failure continue.
24 We want to serve our kids and to improve ourselves.

25 Well, all this period demands for a lot more

1 detail, information on a federal level for program insight
2 for really being able to describe the condition and the progress
3 of American education and have sophisticated terms in terms
4 that we know that it can help the local states so something
5 about it and not multiply their problems.

6 We collect data under the general act. We are
7 asking for some legislation because we think that we need
8 the Census confidentiality law.

9 At the moment, we assure people that we will try
10 to keep individual identifying information from any publica-
11 tion and we try to do things like use the face sheet which
12 we can tear off the identification and, generally speaking,
13 in cross section service, this isn't much a problem. You
14 don't really have to retain the identify of the individual
15 unit.

16 There is a confidentiality problem because if
17 you talk about a private four-year law university in New Haven,
18 Connecticut and which I just saw in some miscellaneous, every-
19 body knows you're talking about Yale. So for that reason,
20 Yale doesn't and never has.

21 We do have problems, standard procedures
22 established for doing analysis of our tables, doing secondary
23 disclosure. There are some problems there. Don't smile so,
24 Madam Chairman.

25 (Laughter.)

MR. NISSELSO: So that does hamper our ability

1 to serve some of our uses particularly in higher education
2 because, there, there's a tradition for the uses at the
3 institutional levels to compare yours with other institutions
4 who you would like to be the peer of or who consider you
5 their peer and to use that kind of thing for analysis.

6 But the real problems and toughest one of
7 confidentiality will be where you want to do longitudinal
8 studies. So, there, it is necessary to retain the identifying
9 information.

10 To try to give some meaning or more explicit
11 meaning to what I should say, what Julius was saying about
12 tough confidentiality provisions, I don't care whatever the
13 provisions are, whatever the law is, whatever the penalty is,
14 you really cannot guaranty confidentiality.

15 The only way you can guaranty confidentiality
16 is by not having identification there. It is like game
17 theory. If you want to fool your opponent about your strategy,
18 why, you use a random so you don't know it yourself so you
19 can't tip your opponent. So we are trying to approximate that.

20 We try to keep individual identification off the
21 document or off the computer tape that has the individual
22 information. We have one translator between going from a
23 name to the individual and that is on the lock and key and,
24 you know, we try to keep monitoring that.

25 I think we do have some problems of the kind that

1 Sig was talking about. But they are not with our contractors.
2 They are with our own internal people. If you know the DMC,
3 if you know HEW's computer system, you can get anything you
4 want. You just have to know the right numbers to call for,
5 that's all.

6 We think the department itself is very conscious
7 about this. The Assistant Secretary for administration
8 management is now in the process with the help of people,
9 I guess with your advice, too -- thank God -- is in the
10 process of revising the manual which is going to implement
11 things.

12 We look to that to help us. We look for strong
13 endorsement from the Committee with encouragement of OMB to
14 get ourselves legislation that will hopefully let us shake
15 a finger at people and threaten them. But we think we have
16 to try the most we can to just keep the information off, to
17 try to keep identifying information off if that means we are
18 not so efficient. We have already given up efficiency.

19 The greatest efficiency would be to one response,
20 one sample for everything. But we have decided that was too
21 much burden. So we are already hung up on some kind of
22 price and we think that confidentiality, protection of the
23 rights of the individual is very important and it is worth
24 spending money for and it just goes everywhere.

25 When you think of the kids in school who get all

1 kinds of things like, "You're educable, mentally retarded.
2 You're not educable. You're just mentally retarded." Some
3 of this information may have been the result of professional
4 advice and there is no way to protect it if a Congressman
5 comes here.

6 That's what happened here. A congressional
7 committee got some data from the Washington School System
8 and laid it out on the Congress Record. There were names of
9 kids here with all those derogatory data, information about
10 them which they had no opportunity to challenge or to
11 attack.

12 This is an area I think we are getting into
13 which we probably do not have any answers on yet. But we
14 want to try to develop some and that is information which
15 state and local agencies collect on our account. They
16 collect it because we ask for it.

17 We have depended, I think, on the tradition of
18 the ethical profession among school people in order that
19 they are protecting their kids and so on, and they don't want
20 the records and so on. Sometimes, I think the only people
21 I don't want to see the records are the parents, speaking
22 as a parent. It seems like people can find out things about
23 my kids. I can't.

24 But anyway, we think this is an open area which
25 would be a working committee to look at and we would like the

1 benefit of their advice about it.

2 I hope I haven't caused you heart failure, Dave.

3 Thank you.

4 MS. GROMMERS: To the contrary. I'm sure his
5 heart is in very good condition.

6 I want to thank you first of all for your very
7 fine presentation and we are of one great disadvantage in
8 that we are not able to spend much, much more time on all of
9 these. We want to let you know that we hope that this is
10 just a preliminary and that as we are learning more, we will
11 have more questions to be asking.

12 We may have more data on which to base some
13 kind of insights for you and we hope that you will be
14 back, that you will be kind enough to come back to talk with
15 us.

16 I think what we will do is start with Senor
17 Anglero. Do you have a question for any one of the gentlemen
18 in particular?

19 MR. ANGLERO: For all of them.

20 MS. GROMMERS: For all of them.

21 MR. ANGLERO: Thank you very much.

22 Well, I want to try to just make one question.
23 I will say on your statement on possibility of guarantying
24 confidentiality, I like it in some way.

25 I just want to ask what is the linkage in this case

1 of all the HEW Centers of statistics, of the Office of the
2 Assistant Secretary of planning and evaluation?

3 MR. SCHOR: What is the relationship?

4 MR. ANGLERO: The linkage to all of HEW centers,
5 as such, with the Secretary of planning and evaluation?

6 MR. NISSELSON: Functionally, we have relation-
7 ships where they have overview of evaluation in the Office
8 of Education and we have participated with them and with the
9 Director of educational evaluation, on studies of education
10 data collection that I have been consulting for them, and
11 have even done some operations for them. Is that the kind
12 of thing you have in mind?

13 MR. SCHOR: I think you might consider them as
14 users of our data. They need data for the evaluation and
15 come to the Center.

16 MR. ANGLERO: Do you find out that this data is
17 used in terms of their responsibilities, long-range planning
18 and all this?

19 MR. SCHOR: Of course they are one of the many
20 users of it. Congress expenditures budget, et cetera.

21 MR. CARROLL: I think that probably all of us
22 sort of skipped what we figured that lots and lots of people
23 had already told you.

24 Every agency like ours has a lot of different
25 complaints. We have requests from the Congress. We have

m 1 requests from the Secretary's Office, particularly this
2 planning group. We have requests from the Commissioner
3 himself, other parts of the agency and so on.

4 We just assume, you see, that since they know
5 we have the information, when we have a problem we will try
6 to get us an ultimate mechanical question. In many cases,
7 unless you have had sense enough five years in advance to
8 know what is being asked, you are not going to be very helpful.

9 That is why it is extremely important to have
10 research organizations where the people come from sufficient-
11 ly wide spectrums of the professions that are watching what
12 is going on and to be able to anticipate things.

13 The kind of research in modern society that we
14 are talking about takes a lot of time. There is a big, long
15 lag time, and so part of our function is to work carefully
16 with these people who are trying to answer questions. What
17 will the department be doing in the next few years? And who
18 are responding to congressional initiative?

19 We work closely with them not just on what they
20 want right now, but what we think they will be wanting,
21 you know, in a few years.

22 For instance, it would have been absolutely no
23 use at all two years ago to try to help the people who were
24 interested in this disability if we hadn't put the disability
25 in the field survey in the year of 1966, you know. We would

1 not have any information.

2 MS. GROMMERS: Does that answer your question,
3 or would you like to draw that out a little bit more?

4 MR. ANGLERO: Let me say I would not, at this
5 moment. Maybe we can talk about this at another opportunity.

6 I would like to see a better explanation in
7 terms of relationships between them and the whole process of
8 decision making and planning, if that is okay. But it would
9 seem better not to pursue on this question.

10 MS. GROMMERS: One point you were really asking is
11 when the data all get together with the bureau of planning,
12 does it in fact get together all at one time?

13 MR. ANGLERO: Well, if there is a system
14 established to do that.

15 MR. CARROLL: Yes, there definitely is. The
16 Secretary's Office has a set of program memoranda. In fact,
17 I am not at a meeting this afternoon because I agreed to
18 come here and where I was supposed to be looking at what our
19 response would be to the program memoranda on income
20 maintenance which the departments put together over the last
21 few months and we have seen several drafts on that. We have
22 commented on that. We have talked to people who put it
23 together. They have requested reams of information on it for
24 us and we have had to make whole series of estimations and
25 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. NISSELSO: It may be that the department has finally decided not to cross that --

MR. ANGLERO: Just a question for --

1 MR. NISSELSON: You have the evidence that this
2 is now going to happen, as I understand it.

3 MR. CARROLL: Well, I think that I'd make a
4 comment on that, that this is the evidence that people
5 realize that this is the problem. But the solution is a long
6 ways off if you are talking about how you are going to talk
7 about national statistics and take statistics from not only --
8 I mean, talk about 54 units. He's talking about hundreds
9 and hundreds of units that report when they feel like it.
10 That's the real problem.

11 When they feel like it, they report to him. If
12 they don't feel like it, he has no way to make them report.
13 How are you going to get those together?

14 MR. NISSELSON: We think there is a way to do
15 it but it isn't by melding.

16 MS. GROMMERS: Please go on.

17 MR. NISSELSON: We see the same thing happening
18 where you have a great deal of local autonomy and a great
19 deal of inability to communicate and it is hard to know what
20 people are talking about at different levels. They talk about
21 programs.

22 Well, everybody's got their own definition of
23 programs.

24 The Office of Education has a long cooperative
25 tradition of putting out handbooks which are presumably

1 standard data elements and should provide means of communica-
2 tion. It is an honorific assignment to be asked to be on a
3 handbook committee. And Al Lichtenberger who talked to you
4 is probably the best man in the Department of HEW and more
5 people know his name than Secretary Richardson, believe me.
6 David Martin, really, if you want to get along with education,
7 you stay close to Al Lichtenberger.

8 The definition of a part-time pupil, in our
9 handbook, is a pupil who goes to school less than full-time
10 as determined by the state.

11 (Laughter.)

12 MR. NISSELSO: I mean, the intellectual content
13 is hard to find. Essentially, we have attempted to keep
14 two classes of accounts: part- and full-time. Maybe it
15 serves the purpose of getting the full-time pupil in the
16 end.

17 We think we have to get the people on the same
18 kind of state, local, federal system that Walt was talking
19 about, which they are doing in a different way in health
20 but are trying to approach the same kind of thing.

21 We think we have to get people together but they
22 are running out of money. If revenue sharing means anything,
23 it means they can't pass the law anymore. Now, U. S. Revenue
24 can have four people who are filling out forms on Ford Motor
25 Company. Now, they only have Ford Motor's federal revenue and

1 when Ford's revenue -- when they find out something's wrong,
2 they'll say, here, you close the sale and pass it along; the
3 state analogue can't -- the state analogue privileges get
4 their privilege by educating kids. There isn't anybody in
5 our level doing anything for educating them and the state
6 department isn't. The state department isn't. It is all at
7 the local level and if they can do it with the grass roots
8 level at my state, that's great. Nobody cares about what
9 information or data they have.

10 If we want to find out, we have to create some
11 systems. We have got to go to the federal government. It has
12 got to pay its share of the pay initiative, of getting people
13 in and agreeing on what is some kind of core data that we
14 need to know at all levels and we think that's the way to
15 do it. You're not going to get it by mashing things together.
16 You're going to get it by making the systems work together and
17 getting the resources that are required, and I think the
18 people at the local level are responsible. They don't give
19 you things that they know are wrong and I have not yet to
20 find people in education who don't really want to do something
21 for the kids. They don't like parents nor accountants but
22 they do like kids and they want to help them but they will
23 give you the facts if you will give them a chance.

24 Excuse me.

25 MS. GROMMERS: Do you have a --

1 MR. NISSELSON: We call that program CCD-7, the
2 Common Core of Data for the '70's. Very unimaginative.

3 MS. GROMMERS: Do you have a description of
4 this in your provision for privacy protection of individuals
5 in the --

6 MR. NISSELSON: Well, it has some intentions about
7 it. We have asked for legislation for confidentiality and
8 we hope to get it with the help of the department.

9 MS. GROMMERS: Could we have copies of whatever
10 documents you have up there?

11 MR. NISSELSON: Yes. Right. It may be a little
12 more informative and less purposeless.

13 MS. GROMMERS: Mr. Siemiller.

14 MR. SIEMILLER: I'll pass. It's getting late.
15 We'll have him back.

16 MS. GROMMERS: Mr. DeWeese.

17 MR. DE WESSE: I pass.

18 MS. NOREEN: I pass.

19 MS. GROMMERS: Mr. Gentile.

20 MR. GENTILE: At the risk of alienating everybody
21 in the room, I will.

22 MS. GROMMERS: You certainly don't have to pass.
23 You're going to be here for another 20 minutes.

24 MR. SIEMILLER: You must be kidding. You may be.

25 MR. GENTILE: A few statements were made. One is

1 the statistical centers can have confidentiality by
2 eliminating the only trace of identification which I agreed
3 to. If we eliminated the identity of the person in the file,
4 we don't have this risk. Assuming also that we took some
5 precautions on small statistical samples that revealed the
6 same thing, what I am more concerned about is not so much
7 about what goes on in the statistical centers that you have
8 run, as much as I am about -- what is it? -- twelve or more
9 billion dollars that goes out to the state in Mr. Schor's area
10 of social rehabilitation services --

11 MR. SCHOR: More than that.

12 MR. GENTILE: And I am concerned about the lack
13 of enforcement of confidentiality in the states.

14 You mentioned that there are SRS approved plans
15 that have very strong confidentiality statements in there,
16 but that they are not implemented and I think perhaps audit
17 procedures ought to be established. I realize this requires
18 budgets but operations of audit are certainly in order if you
19 are going to accept responsibility for the programs that
20 you fund.

21 And I am also concerned about the many things
22 that I feel can be done that we have not done and I am not
23 saying you gentlemen, I am saying we in this room, we in this
24 whole nation. There are many administrative things that we
25 can do. I do not believe that privacy or good administration

1 can or necessarily should be legislated, setting up require-
2 ments for the operations of data centers, establishing
3 custodial responsibilities, all the things on our check list.
4 Many of them can be done within the current framework without
5 any change in legislation.

6 I think there are very, very few that cannot
7 be accomplished without new legislation and perhaps one
8 that comes to mind immediately is something Mr. Shiskin
9 brought up about the subpoena, needing legislation to exempt
10 files from subpoena.

11 So I bring this to your attention because where
12 you ask us, what would we recommend that you do? We are
13 similarly asking you as administrators, what do you do or
14 what would you do within your current framework?

15 Now, at the completion of this Committee's work,
16 I would hope that we would have some guidelines, some sample
17 regulations or quality assurances and systems development,
18 procedures, codes of ethics, whatever that we will present
19 to you in the hope that it would get on down to states and
20 local governments. And, incidentally, I am from the state
21 so I am not talking against anybody but myself and colleagues.

22 MR. SCHOR: Is there any truth of what I suspect
23 that goes on at the state level?

24 MR. GENTILE: Well, you have said a lot.

25 MR. SCHOR: Concerning filing of confidentiality

1 disclosures?

2 MR. GENTILE: Strangely enough, I am not aware
3 of a single case of violation of an individual's privacy
4 in a state, and this would lead me to another point.

5 You mentioned that we have to be very careful of
6 the potential problems that centralized data operation creates.
7 I might add that they sometimes solve some problems, too, and
8 just because we might have 20 or 30 agencies operating in the
9 same computer center doesn't necessarily mean that we have
10 less privacy or less protection or less security.

11 If we administer properly in a central data
12 center, we would have better security than if we had it
13 decentralized.

14 If we administered beter in a decentralized
15 unit, we would have better than in the centralized. So again,
16 I bring up the point that administration plays the key role
17 in this and that we cannot wait for legislation.

18 And to get back to Mr. Shiskin's comments, my
19 understanding from reading the Federal Register some while
20 back concerning the new role of the Office of Management and
21 Budget was that the Office of Management and Budget would
22 get precisely into these things, into management information
23 systems and the kinds of guidance that must come from some-
24 where, and I don't think it is going to come from the legis-
25 lature or the Congress. It's got to come from administrators

1 and I say this not as an indictment to you gentlemen but to
2 all of us people in this country.

3 MR. SCHOR: It must be understood, too, that we
4 are talking, besides legislation, of the necessary resources
5 to carry out orders such as you suggested. It takes
6 money. It takes time.

7 MR. NISSELSON: There's a lot of this.

8 MR. GENTILE: We do live in an economic world.
9 We can't do everything that ought to be done, so we have to
10 choose and set priorities and I would think that this being
11 one of the key elements or paramount concerns, we should
12 establish a high priority for it.

13 MR. SCHOR: All right.

14 MS. GROMMERS: Did anyone else like to come back
15 to some questions? Would you?

16 MR. ANGLERO: Well, yes. I found out through
17 the Chairman yesterday, or somebody commenting on something,
18 I find out that there is some kind of difference when we
19 get the people from the Office of Education yesterday that
20 came. I figured out that there is a kind of approach that is
21 very much different for that kind of approach than the one I
22 know in professional welfare and this. And it looks to me,
23 yesterday, it looks to me confirmed today that there was an
24 effort not to get involved too much in state and local
25 affairs in terms of education, trying to establish some kind

1 of common generals and language source to communicate. But
2 in the other programs, those which I know, it's different,
3 completely different. So it's a process with one agency.

4 I'm just looking here at the transitional chart
5 of the administration of welfare. It looks to me somehow
6 strange how it happens. That's why I make the question.

7 Why do we have different approaches in terms of --
8 or different kinds of structural centers? I was asking the
9 bureau of budget -- management and budget. They do have
10 total responsibility. They do have in budgeting and in
11 management.

12 MR. GENTILE: I think -- I think I followed your
13 point along the same line. To intervene in some way or
14 advise, what is your advisability in this aspect?

15 MR. CARROLL: I'd like to make a comment because
16 I think you thought the answer was nonresponsive. What we
17 were trying to say earlier when you decided we'd come back
18 later was that the programs that Sig is talking about are
19 not national programs.

20 They are programs that if you pick one state,
21 you look at the situation. You go to the next state and it's
22 different. You go to the next state, it's different again.

23 And he has to keep track of all that, all that
24 variety. But in the program that I'm talking about, it's a
25 national program and, therefore, we don't have some of his

1 troubles. I think what I would say is, suppose HRL passes,
2 then you fellows will find out how difficult it is. I have
3 said that in the beginning.

4 If the Social Security Administration has to
5 pick up part of the, let's say, aged, disabled, blind on a
6 part basis, we give them a retention. But they also retain
7 in some states, program assistants, supplements plus having
8 the services then, you know. We already are trying to plan
9 what kind of statistics would we -- will we need, because if
10 we don't plan what kind of statistics we will need, there's
11 no way in the world we will be able to keep track if
12 legislation passes.

13 So we have been busy trying to figure that out.
14 But it is much more complicated than what we have been doing.

15 Now, our office used to do that because you know
16 that HEW didn't have welfare and the social security program
17 split before, and early in 1963 they were together. I wasn't
18 there, but they were there, and they have a lot of experience
19 in dealing with that.

20 But when they made the separation of welfare and
21 the social security programs, broke them apart, the people
22 had to keep up with all these variations in all the states.
23 They had a mammoth problem, plus no teeth.

24 You know, are you going to tell the state, "Look,
25 you either send in the statistics or we're not going to give

1 you the money to feed the children"? They're not going to
2 do that.

3 MR. SCHOR: But there is legislation. They can
4 be held out of compliance.

5 MR. CARROLL: Of course they can, but it means
6 nothing and so --

7 MR. NISSELSO: You don't really want to -- you
8 don't want to starve kids.

9 MR. CARROLL: I don't know about that.

10 MR. NISSELSO: Your kids.

11 MR. CARROLL: What they are saying is a question
12 that --

13 MS. GROMMERS: Excuse me, gentlemen. We're trying
14 to get you all down for the record. We have one staff
15 question that contains an essential piece of information
16 for us.

17 MR. CARROLL: A question I'd like to ask of
18 Mr. Waksberg and I think the best way to ask it is make a
19 statement and invite him to make a statement and correct my
20 statement and perhaps try to answer my question.

21 In connection with the 1970 census, the Census
22 Bureau, it is my understanding, developed a system for coding
23 geographic, small geographic areas down to the block level.
24 This system is alleged in the legislature to have some
25 important uses present among them. It gives the government

1 agencies the ability to reconstruct since they put pieces of
2 census information in about groups of people, geographically
3 defined together in ways that correspond to the
4 jurisdictions of their programs, and this applies to states
5 and localities as opposed to the previous system where one
6 took census tract data, and then tried to -- and then often
7 the census tracts often did not conform to the boundaries of
8 the program.

9 I will give you an opportunity to correct that.

10 My question is: In considering the uses of this
11 geocoding system and as a computer matching technology that's
12 attached to it, has any systematic thought been given by anyone
13 in the Census Bureau or elsewhere, to your knowledge, of the
14 uses that could be made of matching by geographic area, data
15 on groups of people down to a certain level that would provide
16 an acceptable substitute for the uses that are now thought to
17 require matching on some kind of individual-like identifier?

18 MR. WAKSBERG: Well, the answer is yes; a lot
19 of thought has been given.

20 MR. CARROLL: And, if so, could you tell us what
21 they are?

22 MR. WAKSBERG: Well, let me just mention a few
23 additional details. The geocoding system we developed
24 originally for the census. But obviously, when once we had
25 a tool -- there's nothing confidential about this I might say --

1 this geocoding system is simply a method of translating
2 addresses to a piece of geography, geography being an individual
3 block. It might be a tract. It might be a city. But it is
4 an automated system so that if you have any agency -- any
5 agency has a set of records with addresses on it, they can
6 automatically on the computer get a geographic identifier
7 for those.

8 We are making those available to other government
9 agencies, local communities as well as private organizations
10 essentially for two purposes. The purpose you mentioned was
11 one of them; one purpose is because a lot of -- in particular,
12 local planning outfits find it useful to get geographic
13 tabulations of their own administrative records, building
14 permits, for example, building permit information to give
15 information on where construction is going on in the
16 metropolitan area, health records, crime statistics and
17 this is a tool.

18 Now, in addition, this became apparent with the
19 other use, the one you mentioned that can be brought into
20 play, that it is possible to collate other information, let's
21 just say health statistics or birth rates, birth records, it
22 is possible to collate them with social and economic -- or
23 with geographic places, let's say the block, a census tract,
24 some other small area for which census statistics are
25 available. Not individual data but for statistics so that if

1 you want to do some kind of a socio-economic analysis of,
2 let's say, health conditions in the city, you can do them
3 by correlations not with the census information, from the
4 individuals, but census information for the area in which
5 the individual lives.

6 We have a number of cooperative projects going
7 on with localities. There's one in Indianapolis to explore
8 ways in which this can be done most efficiently.

9 There is a fair amount that had been written up
10 on this bit where we have a number of manuals to advise
11 people just how to do the geographic coding as well as
12 potential uses, as well as get other kinds of information.
13 If you want to, I can send you a set of materials.

14 MR. CARROLL: Please.

15 MR. NISSELSON: You do a great job outside of
16 detection.

17 MR. WAKSBERG: Yes.

18 MR. NISSELSON: And that is sent on to the school
19 district for use and now everybody can tabulate the school
20 district.

21 MR. WAKSBERG: We put school districts code, in
22 effect, on census records. The census records, in effect,
23 didn't have that.

24 MR. CARROLL: My question was really -- Thank you
25 very much for straightening that out. My question is,

1 however -- and I wanted to go one step further, Mr. Waksberg --
2 assuming if one could describe knowledged needs of the popula-
3 tion programs, about the population they were intended to
4 affect, could one use information of this sort to get
5 nearly as good usable information that would serve the
6 purposes for which some people argue you've got to match on
7 the individual and develop a positive record?

8 MR. WAKSBERG: At this point, to get into a
9 definition of what is nearly as usable, I'm not sure I know
10 how to answer it.

11 Certainly if you want to correlate it, let's
12 say, with health, with social and economic information, you
13 are best or better off using information for the individual
14 himself.

15 As soon as you go to some broader areas such as
16 geographic areas, you are making some kind of compromise. You
17 are weakening your ability to analyze the data.

18 Now, we say that this weakening is necessary.
19 You know, because of confidentiality provisions, we cannot
20 hand over information to the police commissioner of Washington,
21 D. C., information so he can correlate his prime statistics,
22 so you're making some kind of compromise there. You can get
23 usable information. How much you lose in this kind of process
24 is hard to state in any quantifiable purpose.

25 For some purposes, the loss may be trivial. In

1 others, it may be very useful. I don't know how to answer
2 your question.

3 MS. GROMMERS: Thank you. That's a very
4 beautiful answer.

5 MR. NISSELSO: There has been an attempt at
6 manpower training programs by following up people in social
7 security, their earning records and at least in some
8 instances it was not possible to get marginal data but total
9 sets of three data. I believe you can get information about
10 how satisfied people were with that kind of comparison and
11 that kind of evaluation.

12 MS. GROMMERS: Thank you. You had one point, too,
13 that you wanted to make.

14 MR. JUSTICE: The discussion we have had today is
15 primarily on some of the things that Mr. Shiskin mentioned
16 earlier and have centered on the question of confidentiality.

17 One of the things which was brought up in the
18 hearings on the 1970 census, at least in my interpretation
19 of the hearings, is that a lot of people here think the mere
20 extraction of the information is an invasion of privacy.

21 This would seem to have significant effect effectively
22 in statistical data banks where once it is statistical, you
23 cannot of course insure the confidentiality. And since we
24 have not addressed this issue of whether the extraction of
25 information is or is not an invasion of privacy and what can

1 be done about it, I would like to hear some comments on
2 that.

3 MR. WAKSBERG: I am not sure I understand your
4 question. Is it that the very process of asking for
5 information involves invasion of privacy?

6 MR. JUSTICE: People feel that being mandated
7 for one reason or another, feel forced to give information
8 which they normally would not give about themselves, that
9 that is an invasion of privacy.

10 MR. WAKSBERG: Yes, it is an invasion of privacy.
11 I suppose society has to reach a conclusion whether the
12 benefits of getting the information are worth the infringement.

13 In some cases, I think there are some kinds of
14 answers. As I mentioned earlier, in the 1970 census, we felt
15 that if we asked for social security numbers, it would enable
16 us to provide some marginal additional information. But we
17 regarded the additional information we got was not that great
18 a value, that it was worth doing.

19 I suppose you can ask that about almost any
20 question you can ask in the census. At present, Congress has
21 agreed that the loss to the individual is not great enough
22 to make up for the gains for society. Other people can take
23 different points of view.

24 MS. GROMMERS: Do you think Congress has looked
25 at it in that light?

1 MR. WAKSBERG: Oh, certainly. These issues of
2 the effect on the individual, both on the point of invasion
3 of privacy and on the burden of responsibility, have been
4 taken up often in congressional committees.

5 MS. GROMMERS: Could you get us some of the
6 hearing documents?

7 MR. WAKSBERG: I'm sure we could.

8 MS. GROMMERS: Mr. Simmons wanted to respond to
9 this, too, I believe.

10 MR. SIMMONS: I might say that in our case, all
11 of our information is secured on a voluntary basis. Now, it
12 is quite true that we use various devices, some of them
13 perhaps a little settled and some of them not so settled, to
14 persuade the respondent to give the information. But we do
15 also have the principle that we must have his informed consent.
16 He must understand that this is possibly what it is that we
17 are trying to do and this, of course, gives you a delicate
18 operating problem because you do not want to endanger your
19 respondent's right, too.

20 If I may, let me read a brief paragraph of one of
21 our publications. We are dealing with this question of
22 privacy and confidentiality simultaneously, and we are saying:

23 "This is an instance of the fundamental proposition
24 that in a democratic society each individual must give up a
25 little bit of his freedom in order to insure that both he and

1 his neighbors live in a free society.

2 "To be more specific, the federal statistical
3 information system asks that each citizen truthfully provide
4 to the government on request certain pieces of needed
5 information which he might prefer, for one reason or another,
6 not to report, and to do so in order that the government
7 can carry out its programs more wisely and more efficiently
8 for the benefit and welfare of all the citizens.

9 "Similarly, even though that government possesses
10 certain items of information, the individual citizen must
11 sacrifice a small amount of his freedom, and be restricted
12 from having access to that information in order not to
13 transgress the rights of privacy of other citizens."

14 I think that describes our position on that
15 topic generally.

16 MS. GROMMERS: Could we give that to the steno-
17 grapher for the record afterwards?

18 MR. SIMMONS: Yes.

19 MS. GROMMERS: I have one question that one of
20 our members would love to have addressed to you, Doctor
21 Nisselson, and he is with the Department of Education with
22 the State of Florida.

23 He says with respect to the longitudinal study
24 of educational effect, data are collected from individuals.
25 These data are maintained with persons identified in some

1 way, as we heard in some way earlier today, earlier in our
2 meetings.

3 His questions are, one: What assurances are
4 given to the individuals regarding confidentiality?

5 Two: Are the assurances, if given, enforceable?
6 For example, under the Freedom of Information Act, are the
7 data subpoenaable?

8 Three: What measures is USOE taking to assure
9 confidentiality?

10 And, four: Are measures taken for this weaker,
11 stronger or the same as measures taken with other similar
12 efforts in their work?

13 MR. NISSELSO: If the comparison is in OE, the
14 comparisons were taken a little stronger.

15 The assurance we give the individuals essentially
16 are that we undertake to try to assure that we will not
17 release data in the way that individual information could be
18 identified to an individual.

19 And the devices that we are trying to use to
20 help assure that are of the kind that I talked about earlier.
21 I think that you know we are taking a great many steps which
22 we think, in trying to maintain a kind of discipline, that
23 Mr. Gentile was talking about. We don't have any ultimate
24 sanction though, and it is for that reason that we think
25 that we would like to have legislation of the kind that

1 Julius Shiskin was recommending for all agencies.

2 MS. GROMMERS: Thank you very much.

3 We have one more question and then I think we'd
4 better thank you all very much for coming.

5 (Private discussion between panel members.)

6 MR. NISSELSO: Partial monitor. Say, our
7 instructions tell a student that he doesn't have to reply.
8 The response is entirely voluntarily.

9 MR. CARROLL: I wrote a question out. I
10 originally intended to address it to Mr. Waksberg, but it
11 appeared to me it is an appropriate question for all five
12 of you.

13 I'd preface my question in saying that the
14 Committee is interested in locating hard data, shall we say
15 serious social science research, on the perceptions that
16 people have of what is private and of the behaviors that are
17 associated with privacy in the contexts that are recorded by
18 people regarding privacy, and the circumstances under which
19 these perceptions are held and they are not.

20 The reason I wanted to address this to Joe is
21 that the Census Bureau at some point has looked into how the
22 confidentiality pledge is attached to the census and are
23 perceived by the respondents and also, conversely, the money
24 to the respondents. And I wonder if he would tell us something
25 about that for the record and whether these other statistical

1 centers represented here have done any research of that sort
2 on however large or small a scale.

3 It would give us some greater insight than one
4 gets in the rhetorical literature about the significance of
5 privacy in an individual's life in certain circumstances
6 today.

7 MR. WAKSBERG: I am not sure I can give you any-
8 thing more than other case studies.

9 I don't know of any real research that has been
10 done to get people's perception either on the general notion
11 of privacy or confidentiality or where they stand relative
12 to the government when the government comes around with
13 questionnaires or whether they are more concerned about
14 earnings in privacy or confidentiality for some items than
15 for others.

16 We do have hard statistics on such things as
17 refusals in our voluntary service, how many people refuse to
18 give information at all. We have information on how many
19 people refuse to answer specific questions and, there, I might
20 say that the general folklore which is brought out by some is
21 that income is by far the general subject, much more so of
22 what most people will consider private.

23 MR. NISSELSO: What about that experience in
24 business surveys, giving your respondents an explanation?

25 MR. WAKSBERG: I'm not sure what you mean.

1 MR. NISSELSO: This was actually a respondent's
2 current business sales. Half of your people gave the
3 explanation why the government wanted the sales last month.

4 "Why do you want it?"

5 "I don't know why they want it. I'm just getting
6 paid for it."

7 The other thing was it was an extra value to the
8 businessmen, and the remarks were remarkably lower which is
9 to pay the respondents, which is self-interest rather than
10 the government wanting it.

11 MR. WAKSBERG: Let me see if I can answer your
12 question.

13 MR. SHISKIN: Was that really a survey? I had
14 the story it was a one-man survey.

15 MR. WAKSBERG: In connection with people's
16 perception as to what the extent is to the government, how
17 confidential is confidential data, we don't have any surveys.
18 But we have lots of impressions around that.

19 This is sort of a bewildering notion to people
20 and, number two, they are very skeptical when we talk about
21 confidentiality in that we mean it and that there is a
22 general feeling of, "Yeah, we have it in our files. If the
23 F. B. I. wanted information, of course, they will be
24 available to them."

25 They don't realize that if the F. B. I. wanted it,

1 they don't find it in our files. It is not a confidentiality
2 that you have. It is just general bureaucratic ineptness.

3 But certainly, the evidence that we have is
4 that people don't really trust these statements of
5 confidentiality. I shouldn't use the word "evidence."

6 MS. GROMMERS: If we could get any documentation
7 on any of this, we would be very grateful. We would like
8 to have surveys about which questions they did not answer,
9 for example.

10 MR. WAKSBERG: Actually, this is tabulated in
11 all our census volumes in terms of number of responses,
12 item by item, how many people didn't answer, age; I can
13 produce a few tables like that.

14 MS. GROMMERS: But you never investigated why?
15 You simply tabulated them?

16 MR. CARROLL: Some of the methodological
17 tabulations might interest you.

18 MR. NISSELSO: Different interviewer groups
19 like the HIP study center.

20 MR. WAKSBERG: How do you interpret that in the
21 context of the question?

22 MR. CARROLL: Oh, Joe, may I call you by telephone
23 and ask you?

24 MS. GROMMERS: I think we are going to thank you
25 all very, very much for being with us and staying with us so

1 late and accepting our invitation to come back and join us
2 again.

3 (Whereupon, at 5:30 p.m., the Committee meeting
4 was adjourned.)

5
6 * * * * *