

ACS Release of CA CPS II Subject Addresses to Jerrett Violated
1982 ACS Confidentiality Agreement with CPS II Subjects

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1982 ACS CPS II Instructions for Researchers (who enrolled all subjects) (See Attached PDF)

“SOME QUESTIONS YOU MAY BE ASKED BY PEOPLE YOU ENROLL

Q. Will the information on the questionnaire be kept confidential?

A. Yes. It will be used only for research purposes. We will **never** release information about any particular person and will not release addresses to any agency for any purpose, whatsoever.”

1982 ACS CPS II Fact Sheet (given to each enrolled subject) (See Attached PDF)

“QUESTIONS YOU MAY HAVE ABOUT THIS STUDY

Q. Will my information be kept confidential?

A. Yes. We will use it only for research purposes and will not release addresses to any agency for any purpose.”

January 25, 2007 Jerrett CARB/UCB Contract Agreement No. 06-332: “Spatiotemporal Analysis of Air Pollution and Mortality in California Based on the American Cancer Society Cohort” (<http://www.scientificintegrityinstitute.org/Jerrett012510.pdf>) and

(<http://www.scientificintegrityinstitute.org/CARBBook012507.pdf>). Page 13 of 87 states:

Using the monthly pollutant data discussed above, exposures, for the first time, will be assigned to the subjects’ baseline addresses. We have received approval from Drs. Michael Thun and Jeanne Calle to have a GIS consultant, Zev Ross, go on-site and geocode all available addresses. Once geocoded at the ACS in Atlanta, the locational information will be brought by hand to the University of California, Berkeley, where exposure assignments will be completed. Data will then be transported by hand to the University of Ottawa and linked to the master analytical file there for analyses as described below

July 11, 2008 CARB “Tran” PM2.5 Mortality Teleconference Transcript: Jerrett describing to Enstrom ACS CPS II subjects in CA being geocoded for PM2.5 exposure based on their address (<http://www.scientificintegrityinstitute.org/CARB071108.pdf>) and (<http://scientificintegrityinstitute.org/CARBTeleconference071108.wav>)

(0:55:18 Hours:Minutes:Seconds of Teleconference)

“**Jerrett:** I’m willing to share exposure estimates, but I would point out that that would require a separate ARB approval and we’d have to get all the locations and approvals from ACS because the location is here. I have...and the CPS II data are being hand delivered, flown out here, to be picked up in Atlanta on Monday and coming out Tuesday and then I’m putting them into an 1800 pound safe that’s got a 2 inch metal door on it, you now, highly secure. So, this is not something, we don’t ever exchange these data by mail or any other means. So it’s going to mean that we would have to go back out to Atlanta and geo code this older cohort. We’re not going to get as a good an address match because the GIS files going back in time are pretty sparse. Then we would have to bring it to our lab and assign the exposures as we’re assigning the other ones.”

February 26, 2010 CARB Symposium

"Estimating Premature Deaths from Long-term Exposure to PM2.5"

(<http://www.cal-span.org/cgi-bin/archive.php?owner=CARB&date=2010-02-26>)

During Symposium Michael Jerrett read this ACS CSP II Data Access Policy Statement

(3:22:30-3:24:50 Hours:Minutes:Seconds of Symposium)

“I have one important statement that was sent to me by the American Cancer Society and that is that the American Cancer Society appreciates and fully supports the value of independent analysis particularly when it comes to issues of public health for which there are political and commercial interests. This is why such examinations undertaken regarding American Cancer Society CPS II analysis of air pollution is the most influential study of small particulate air pollution, particularly the Pope study. Because the geographical location is a key component of the analysis there is no way to de-identify the data. The geographic address is the key to the analysis. Releasing the data publicly would expose American Society to charges of unethical practice. It’s hard to imagine an institutional review board that would sanction the release of data in which names and addresses are included.”

Enstrom Conclusion

In 2008 or earlier, when ACS gave address information for geocoding to Jerrett, et al. they violated their 1982 agreement with CPS II subjects to keep questionnaire data, particularly addresses, strictly confidential. This violation has already occurred and has nothing to do with the US House Science Committee request for de-identified data on CPS II subjects.

AMERICAN CANCER SOCIETY
CANCER PREVENTION STUDY II
INSTRUCTIONS FOR RESEARCHERS



GENERAL INSTRUCTIONS:

Enroll about ten families; by families we mean households in which one or more persons live as a family unit. Each family must have **at least one person over the age of 45**. Please make a special effort to include families with people in their 50's and 60's. Enroll only those families you are reasonably certain will remain in the area for the next six years. If you can enroll more than ten families, please do so.

To help explain the purpose and plan of the study, leave a "Cancer Prevention Study II – Fact Sheet" with each family you enroll.

In each of the enrolled families, request that every member **over the age of 30** fill out a questionnaire, place it in the "Confidential Envelope," seal it and return it to you. Because of the size of the study, it is necessary to identify every questionnaire by a series of numbers. This is explained in item 3 below. Please follow the instructions carefully.

After collecting the questionnaires, fill out the four-page "List of Families and Persons Enrolled" folder. Include on this the name and address of a person who knows most of the enrolled families and who can act as a **substitute** for you during the next six years, if necessary. When this is completed, wrap the "Confidential Envelopes" (containing the completed questionnaires) in the "List of Families and Persons Enrolled" folder, secure with a rubber band and place in the large envelope. Deliver all completed materials according to the instructions you have been given.

DETAILED INSTRUCTIONS:

1. Check this packet to be sure that it contains:

- a) a supply of questionnaires for men (printed on blue paper);
- b) a supply of questionnaires for women (printed on white paper);
- c) a supply of "Confidential Envelopes;"
- d) a four-page "List of Families and Persons Enrolled" folder; and
- e) a supply of "Fact Sheets."

2. On the back of this instruction sheet, list the families (households) you know in which there is at least one person over the age of 45. The term "household" includes people living together as a family unit and also includes single persons living alone.

Visit each family on your list and enroll only those you feel will be in the area during the next six years. Request that every member **over the age of 30** fill out a questionnaire. Do not exclude a family if one or two members refuse or fail to fill out a questionnaire after others have done so.

3. For purposes of identification, you have been assigned a Division No., Unit No., Group No., and Researcher No. Copy these numbers onto all questionnaires and confidential envelopes you use. In addition, be sure to enter all these identifying numbers, your name and address, and the name and address of a substitute who knows most of the families you have enrolled, on the top of the "List of Families and Persons Enrolled" folder.

Assign a Family No. to each family you enroll, the first being Family No. 1, the second being Family No. 2, etc. Also assign a Person No. to each person you enroll in **each** family, one member of a family being Person No. 1, another being Person No. 2, etc.

For example, your first family (Family No. 1) may consist of Mr. and Mrs. Doe; their 35-year-old son, Paul Doe; the wife's mother, Mrs. Smith; and a friend, Mr. Johnson. Thus, for Family No. 1, Mr. Doe is Person No. 1, Mrs. Doe is Person No. 2, Paul Doe is Person No. 3, Mrs. Smith is Person No. 4, and Mr. Johnson is Person No. 5. Next, Mr. and Mrs. Brown may be Family No. 2; Mr. Brown being Person No. 1; Mrs. Brown, Person No. 2, etc. in the family.

4. When a person agrees to fill out a questionnaire, write his or her name and all of the identifying numbers (including Family No. and Person No.) at the top of a questionnaire. Also write his or her name and **address** and all the identifying numbers on a "Confidential Envelope."

Give the questionnaire and the "Confidential Envelope" to the participant. The questionnaire is designed to be filled out by the person **and the answers are confidential**. Ask that the participant fill out the questionnaire and then put it in the envelope and seal it. You are responsible for collecting the sealed envelopes. You may either wait while the participant completes the questionnaire or, if you prefer, you may leave the questionnaire and return some time later to pick it up.

5. Try to enroll all your families and collect the filled-out questionnaires within two weeks.
6. After you have collected completed questionnaires from all the people you have enrolled, fill out the "List of Families and Persons Enrolled," according to the instructions printed on this blue folder.
7. After this is completed, wrap the "Confidential Envelopes" in the "List of Families and Persons Enrolled" folder, secure with a rubber band and place in the large envelope and return it according to the instructions you have been given.

PURPOSE AND PLAN OF THIS STUDY

The first American Cancer Society Prevention Study was conducted over a 13-year period, from 1959-1972, and helped us identify a number of factors related to the development of cancer. In fact, most of what we know today about the causes of cancer has come from such epidemiologic studies. Cancer Prevention Study I, for instance, established cigarette smoking as a cause of lung cancer and implicated tobacco use in the development of other cancers, and heart and respiratory diseases. Other epidemiologic studies have linked skin cancer to a heavy exposure to X-rays, arsenic or certain types of tars and oils, bladder cancer to workers exposed to certain chemicals, and lung cancer to a long-term exposure to asbestos fibers. These are some of the environmental factors which can cause cancer. It is only by following a large number of people for a long period of time, as we plan to do in Cancer Prevention Study II, that we can uncover many other factors and determine which are hazardous to health and which ones are not.

In Cancer Prevention Study II, we are going to turn our attention to the changes that have occurred since our first study in the way we live, the products we use, and in our home and workplace environments. Recently, there has been widespread concern about the safety of saccharin, hair dyes, oral contraceptives, tranquilizers, and other drugs and medications. The effects of long-term exposure to X-rays, air and water pollutants, and carcinogens in the workplace have also been questioned. The

public and the scientific community want to find out the reason for the increased rates of cancer in black populations and pinpoint the special cancer risks among other minorities.

The plan of the American Cancer Society's new Cancer Prevention Study is to enroll more than 1,000,000 persons and to follow them for six years, and perhaps longer. As a volunteer researcher, you will be instrumental in helping to assemble vital research data. By keeping track of the persons you enroll, and reporting on them every other year, you will provide our health statisticians with information on how life-styles affect health and what factors either increase or decrease chances of getting cancer and other diseases.

Such an endeavor will add to our knowledge of cancer and enable us to identify those factors which cause cancer and can be controlled, as well as those which do not appear to increase risk of developing cancer. The final goal, of course, is to prevent cancer and save thousands of lives.

SOME QUESTIONS YOU MAY BE ASKED BY PEOPLE YOU ENROLL

Q. Why was I selected for this study?

A. We need to enroll a large sample of the American public: people of different ages, geographic areas, races, religions, habits, exposures, and life-styles. This way we'll find out which groups have higher cancer risks and which have lower ones.

Q. Are you interested mainly in people with cancer?

A. No, we are interested in all people, those who are in good health, as well as those who have or have had cancer.

Q. My 25-year-old son lives with me. Why don't you want him to answer the questionnaire?

A. We are excluding people below 30 because they have not been exposed to the factors under study as long as older people have. Also, the frequency of cancer generally increases with age and there would not be enough data to study if we enrolled people under 30.

Q. We already know that cigarette smoking causes cancer. Why do we need another study?

A. The cigarettes now smoked by more than fifty million people are considerably different from the ones smoked at the time of our first study. We need to determine whether low tar and low nicotine cigarettes have substantially affected health risks. We are also investigating the effects of cigarette smoking in the workplace environment and the possible health effects of "second-hand" smoke, that is, smoke inhaled by non-smokers.

Q. Why did you ask for my Social Security Number? Isn't that illegal?

A. Giving us your Social Security Number is strictly voluntary. By doing so, you will save us much time, effort and money in verifying our records later on (especially for people with the same names). Incidentally, it is not illegal to ask for your number; it is illegal to **require** it.

Q. Will the information on the questionnaire be kept confidential?

A. Yes. It will be used only for research purposes. We will **never** release information about any particular person and will not release addresses to any agency for any purpose, whatsoever.

LIST OF FAMILIES:

The plan is a... (faded text)

... (faded text)

SOME QUESTIONS YOU MAY BE ASKED BY PEOPLE YOU ENROLL

Q Why will I... (faded text)

A We need... (faded text)

Q Why do I... (faded text)

A The extra... (faded text)

Q Why do I... (faded text)

A Land is... (faded text)

Q Why do I... (faded text)



Thank you for agreeing to participate in the American Cancer Society's Cancer Prevention Study II. By completing the questionnaire, you will join one million other Americans who are helping us advance our knowledge of the causes and prevention of cancer. Such knowledge will enable us to work toward the goal of preventing cancer and saving thousands of lives.

THE FIRST STUDY: 1959-72

Data for the first Cancer Prevention Study were gathered over a 13-year period, from 1959-72, and helped us identify many factors related to cancer development. Information from study participants on personal habits and lifestyles, family and medical history, physical condition, and workplace exposures provided invaluable information about the risks of cancer. The study was instrumental in clarifying the link between smoking and cancer and in showing obesity is related to certain cancers. Information from the study also furnished data on risks for heart disease, stroke and other diseases. The landmark Surgeon General's Report on Smoking and Health was based in part on data from this American Cancer Society Study.

So far, about 65 scientific papers have been published from data in the study. These include a recent report that cigarettes lower in tar and nicotine reduce, but do not eliminate, the risk of lung cancer.

WHY A SECOND STUDY?

Since the first Cancer Prevention Study, many changes have taken place in the way we live, the foods we eat, the products we use, and in our home and workplace environments. In 1959 few people questioned the health effects of high fat or high cholesterol diets or the safety of many consumer products, such as artificial sweeteners, coffee, or hair dyes. Birth control pills and certain other drugs and medications were only starting to be widely used.

Since 1959, we have grown more aware of pollutants in our air and water, and carcinogens in the workplace. There is also increasing concern over the rising rates of cancer among blacks and the special health problems of minorities. A large study like this is the most effective way to find out which environmental factors increase cancer risk and need most control, and which carry little or no risk.

YOUR PART

Please answer every question. Be assured that the information you supply will be kept *confidential* and will be used *only* for research purposes. Your personal data will never be released to anyone for any reason. Later you may be given a short supplementary questionnaire. If you have any questions about your participation in this study, please contact your local American Cancer Society office.

Again we'd like to thank you for volunteering information that can help the American Cancer Society intensify its efforts in preventing cancer.

QUESTIONS YOU MAY HAVE ABOUT THIS STUDY

- Q. Why was I selected for this study?
- A. We need to enroll a cross-section of Americans: people of different ages, geographic areas, races, religions, occupations, exposures, and lifestyles. In this way we'll find out which groups have higher or lower risks.
- Q. Are you interested mainly in people with cancer?
- A. No, we are interested in all people now in good health, including those who have had cancer.
- Q. My 25-year-old son lives with me. Why don't you want him to answer the questionnaire?
- A. We are excluding people under 30 because the frequency of cancer generally increases with age and there would not be enough data to study younger persons.
- Q. We already know that cigarette smoking causes cancer. Why do we need another study?
- A. The cigarettes now being smoked are considerably different from the ones smoked at the time of our first study. We need to determine whether low tar and nicotine cigarettes have substantially affected health risks.
We are also studying the effects of cigarette smoking in workplace environments and the possible risks of "secondhand" smoke, smoke inhaled by nonsmokers.
- Q. Why did you ask for my Social Security Number?
- A. Giving us your Social Security Number is strictly voluntary. By doing so, you will save us time, effort and money in later verifying our records (especially for people with the same last names).
- Q. Will my information be kept confidential?
- A. Yes. We will use it only for research purposes and will not release addresses to any agency for any purpose.