

Attachment L. Informed consent.

Reading level: 8.4

ATSDR Health Survey of those who lived or worked at Camp Lejeune or Camp Pendleton in 1987 or before

Introduction and Purpose

The Agency for Toxic Substances and Disease Registry (ATSDR) is doing a health survey of those who lived or resided at Camp Lejeune or Camp Pendleton in 1987 or before. ATSDR is conducting this research activity to learn more about the health effects of workplace and environmental exposure to chemicals. We are inviting people who were exposed to chemicals, as well as those who were unexposed, to take part in the survey.

The survey will ask questions about:

- when and where you lived at Camp Lejeune or Camp Pendleton
- your health
- work history, and
- smoking and drinking habits.

The Navy and the Marine Corps are funding this survey. The authority for collecting this information, including your Social Security Number, is the National Defense Authorization Act for Fiscal Year 2008.

Procedures

1. If you agree to participate in this health survey, please complete the enclosed survey. The completed survey should be mailed to Westat, a contractor for ATSDR. Please mail it back in the envelope provided.

If you prefer, you can answer the survey on line at www.xxx.com. You will have the option to take a break. You can save your responses and return to complete the survey at a later time. When you log in again, you will return to the survey at the exact page where you left off.

2. You have the right to refuse to answer any question or refuse to complete the survey.
3. Other than completing the survey, there will be no direct involvement with survey participants. The survey should take about 45 minutes to complete.
4. Information collected as part of the survey will be used for research purposes only. All information will be kept private to the extent permitted by law. Data that identifies you or where you live will not be included in any report.

5. You will be asked to sign a release form so that medical records can be reviewed, which will supplement the medical data reported in this survey.

Risks and Benefits

This health survey involves only data collection through mail questionnaire or over the internet with minimal risk to participants. There will be no lab testing or medical procedures required in this survey.

Some of the questions are of a personal nature, like questions about your health. Answering the survey is voluntary. If you choose not to participate, there will be no penalty. You will not lose any benefits if you decide not to continue.

There are no direct benefits from participating in this survey. However, taking part in this survey will help us learn more about ways to improve health and prevent disease in the future.

Confidentiality

All answers you give will be kept private to the extent permitted by law. You will not be identified by name in any reports from this survey. All information from the surveys will be kept in a locked file. Data will be safeguarded by storing the data separate from any personal identifiers.

If you complete the survey on-line, your privacy will be maintained to the degree permitted by the technology used. Security measures will be taken to protect data submitted over the internet. These include Secure Socket Layer (SSL) encryption and password-controlled servers with limited access.

In order to do this research, ATSDR will need to read and use information about you that is kept in your medical records and other restricted files. When you sign the medical release form, you will authorize ATSDR to locate reports of clinic visits, hospitalizations, and cancer registrations.

The authority for collecting your social security number (SSN) is the National Defense Authorization Act for Fiscal Year 2008. Your SSN will be kept private. We do not plan to share this information with anyone other than ATSDR staff. We will use your SSN for identity verification purposes and to link with your medical data

If you have any questions about this study, please contact the ATSDR Health Survey Hotline at xxx-xxx-xxxx.

For questions about your rights as a research subject, please call the Associate Administrator for Science, ATSDR at xxx-xxx-xxxx.

Participant Consent

I have read or have had read to me the description of the ATSDR Health Survey. I have been informed of the risks and benefits of the survey.

I understand that I do not have to take part in this survey. If I choose not to participate there will be no penalty.

My rights as a research subject have been explained to me. I voluntarily agree to take part in this survey.

The purpose of the survey and how it is being done have been explained to me.

If completing the paper survey: An extra copy of the consent form has been enclosed for my records. I will mail the signed consent form back in the envelope provided.

Printed Name

Signature

Date

If completing the survey on the internet: I can choose to print out a copy of the consent form for my records. I understand that by clicking the “I agree” button, I am agreeing to take part in the survey.