

Public Health Institute (PHI) Consent to Participate in a Research Study

Fire and Water: Investigating Drinking Water Contamination in Paradise, California after the Camp Fire

The purpose of this form is to ask for your voluntary participation in a research study. You have been asked to participate in this study because you are a resident of a community affected by the Camp fire, and your home did not burn down. We are asking that you allow us to collect tap water at your home, and to fill out a brief questionnaire. We may ask some participants later to allow us to collect more tap water and also air samples.

Please consider the following information carefully before you decide to participate. If you wish to participate, please sign this consent form that will allow a researcher to collect a water sample from your home and ask you to complete a short questionnaire.

What is the purpose of the Fire and Water study?

This study will identify if there are drinking water contaminants in household tap water in homes affected by the Camp fire. The goal of the study is to collect information that may help to better understand, identify, and address drinking water contamination after fires.

What will happen in the study?

Researchers will collect tap water from about 175 homes. This water will be tested for over a hundred volatile organic compounds (VOCs), including benzene, a chemical that can harm health at elevated levels. After this, researchers will return to about 20 of the homes to take more water samples and test for a larger group of contaminants. They will also take samples of the air inside those homes to see if contaminants in the water may be getting in the air.

The data collected as part of this study are obtained for research purposes. Researchers will analyze the data, and the findings will be shared with you and the community, and will ultimately be published in a scientific journal. Results for your household will be available to you if you choose to receive them.

Who is conducting this study?

The Fire and Water study is a scientific research collaboration between the Public Health Institute (PHI), the California Department of Public Health (CDPH), the University of California San Francisco (UCSF), and the University of California, Davis (U.C. Davis). The study is funded by a grant from the National Institute of Environmental Health Sciences (NIEHS) of the National Institutes of Health (NIH).

The study is directed by Dr. Gina Solomon. She is a Clinical Professor of Medicine at the UCSF and a research scientist at the PHI, a not-for-profit research institution. Dr. Peggy Reynolds, who is a Professor at UCSF, is a co-investigator in the study. Dr. Paul English, a research scientist at the CDPH will direct the mapping the results and the community outreach. Chemists at BC Laboratory in Bakersfield, CA will test the water samples for volatile contaminants, including benzene. Scientists at U.C. Davis and the EPA National Exposure Research Laboratory will test the samples for a much larger set of contaminants.

Is this study related to other water testing efforts?

The local water companies (Paradise Irrigation District and Del Oro Water Company) and the Division of Drinking Water at the State Water Resources Control Board, are in charge of addressing contaminants in the drinking water system. These agencies are conducting their own investigations

of local water quality. This study is not related to those efforts, but we are using their data to inform our study.

We would like to share results of this study with the water agencies. Because they are responsible for drinking water quality, we believe it is important to let them know if there is a problem at a specific home so they can take action to address it. If you allow it, we will share your water testing results with your water company and the Division of Drinking Water. We will never share your questionnaire responses with these agencies. If you do not allow us to share your results, you may still participate in this study.

Is this study related to other university research projects?

The U.C. Davis study, "Wildfires and Health: Assessing the Toll in NOrthern California" (WHAT NOW California), is collecting information on residents' experiences during and in the immediate aftermath of the Camp fire through online and door-to-door surveys. The U.C. Davis Bio-Specimen and Fire Effects Study (B-SAFE) focuses on women in Northern California who were pregnant during the Camp fire. We are working with the U.C. Davis researchers to invite participants in their studies to have their drinking water tested. We would also like your permission to share the data we collect about your household and water with the researchers at U.C. Davis, to enable them to evaluate possible health effects associated with the water.

What will I be asked to do?

If you choose to participate in the Fire and Water study we will ask you to do the following:

- 1. Sign this consent form indicating that you have read it and agree to participate.
 - If you are a renter, we will need to have the contact information for your property owner/ landlord. We will then ask him/her to read, sign and return a separate consent form to allow the water sampling to be done on the property.
- 2. Allow a researcher to visit your home to collect samples of tap water from your kitchen faucet. This will take about 30 minutes.
 - During the home visit, you will be asked to complete a brief self-administered questionnaire about:
 - Your uses of tap water in your home
 - Any concerns about tap water quality in your home
 - Health conditions you may or may not have experienced recently
- 3. We may re-contact you in the future to re-test your water, and potentially also to test your air and install a "point-of-use" filter on your kitchen tap to collect a sample over a two week period.
- 4. You will be contacted to let you know about a community meeting to hear about the findings of this study. Attendance at the meeting is not required for participation in the study.
- 5. If you tell us that you want the results of the sampling in your residence, we will send the results to you directly.

Are there any risks involved with taking part in the project?

- Providing the water samples poses no known risks. In the unlikely event that any damage occurs to the faucet or your home during the sampling, we will cover the cost of repairs.
- Some questions on the questionnaire may make you feel uncomfortable. You have the right to choose not to answer any question. Your individual answers to questions will not be

- shared with anyone outside of the study staff.
- It is possible that our study will detect chemicals of significance to the community in the water. If elevated levels are detected in your community, it may cause you to feel emotional distress. You will be invited to a community meeting where you will have the opportunity to discuss your concerns and learn more about what is known about these contaminants.
- Receiving your household-level results, if you choose it, may cause you to feel emotional
 distress. Dr. Solomon and other study staff will be available to talk with you personally about
 your study results and answer any questions you may have.
- Receiving your household-level results might indicate that further testing for chemicals or
 water treatment is advisable. The study takes no financial responsibility for any future
 testing or treatment. Although we will offer re-testing in some households, multiple tests are
 outside the scope of this study.
- Receiving your household-level results could create a legal obligation to disclose information about your property to future buyers or occupants, if, for example, the study results indicate elevated levels of benzene from your household pipes.

Are there any benefits involved with taking part in the project?

- By participating in the study, you are:
 - Getting free testing of your tap water.
 - Contributing towards addressing public and environmental health issues in your community.
 - Receiving information about your tap water that may help you to take actions to reduce exposure to contaminants.
- There is no penalty if you decide not to participate or do not want to receive or share your results.

Will I receive my results?

- You will receive study findings that contain the overall results for everyone in the study.
- You will receive test results for your home only if you choose that option on this consent form below. You do not have to receive your individual results. You can also change your mind later. If you change your mind, you will need to sign a new consent form, which will replace the initial consent form.
- If you are a renter, <u>in order to receive results about your tap water</u>, the property owner will need to agree to receiving and sharing these results. If your landlord agrees to the sampling, but not to returning results, you can still participate in the study, but you will not be able to receive the household-level results for the property.

How will my questionnaire and water information be used?

- The questionnaire information you provide will only be used for the purposes of research.
 - If you permit, the results of the questionnaire will be shared with U.C. Davis researchers that are studying the effects of the Camp fire on health.
- The water sampling results will be used for research.
 - If you permit, the results will also be shared with water agencies and used to enhance the general investigation of water contamination after the Camp fire. The results will also be shared with U.C. Davis researchers with your permission.

- Unused portions of water samples from this study will be stored and may be used for future studies.
 - You will not be contacted for additional permission to use your information or household water samples for future research. However, in the event they are used for future research, an Institutional Review Board (a committee concerned with the protection of research participants) will review any such research.
- Results of this study will be shared with your community and will be published, but data will be presented only in aggregate (no individual results will be presented).

How will my identity be protected?

There are always some risks in giving information about yourself to someone else. To minimize these risks, the research team has instituted security procedures to protect your privacy and keep information about you as confidential as possible.

- All personal information obtained in this study will be kept confidential and will be available
 only to Fire and Water study staff. In the event that Dr. Solomon needs to share information
 with a scientist outside of the study staff for the purposes of the study, she will obtain their
 written agreement to maintain confidentiality.
- Your contact information and the information you provide on the questionnaire will be stored in a secured locked file cabinet at UCSF. Electronic data files containing personal identifying information will be maintained on password-protected computers at PHI or UCSF. Any email communications with you will be stored in a separate file and will be destroyed at the end of the study.
- Research information you provide on the questionnaire and the results from your water samples will be stored in electronic file(s), separate from your personal information.
 Information about you in these files will be identified by a numeric code, not your name, or other personal characteristics. The key linking the numeric code with your identity will always be kept in a separate location.
- Water sample containers and filters will be marked with a numeric code, not your name or any other personal identifying information, and forwarded directly to the laboratory.
- All study staff who have access to your personal information are required to sign a
 confidentiality statement and complete a course in the protection of human subjects so that
 they are fully-trained on how to handle and protect confidential data.
- If you are a renter, your landlord will have the opportunity to agree to release the results of
 your water testing but cannot authorize the release of any information you provide on the
 questionnaire.
- General results of this study will be shared with your community and will be published, but data will be presented in aggregate and will not contain any individual level data.
- If you allow us, we will share your results with the local utility and the Division of Drinking Water. We will never share your responses to the questionnaire.
- If you allow us, we will share your results with the U.C. Davis researchers conducting research studies of people affected by the Camp fire.

Who should I contact if I have any questions about the project or my participation?

 For any questions concerning this study or if you are not satisfied with the manner in which this study is being operated we encourage you to contact the Principal Investigator, Dr. Gina Solomon at 415-289-9310, or via email at gina.solomon@phi.org.

If you have questions regarding your rights as a study participant or want to report any complaints or injuries, please contact Robert McLaughlin, J.D., Ph.D., Administrator of the PHI Institutional Review Board (the committee that oversees the PHI research involving human subjects) during regular business hours at 510-285-5500.

We thank you for your interest in participating in the Fire and Water study. Your participation is voluntary. You can decide not to participate and drop out of the study at any time without any repercussions. If you drop out, you have the right to tell Dr. Solomon to destroy any data and C

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samples that you have already provided. If y consent form.	•	
Consent:		
By signing below, I indicate that I have reacceptable answers to my questions, and above. I will receive a copy of this consent for	have agreed to participate in the	•
I understand the limitations and risks assostudy and have answered the following:	ociated with receipt of water sam	ipling results from this
I am the owner of my home and I DC residence.	O / DO NOT (circle one) request the	ne results for my
OR:		
I rent my home and I DO / DO NO understand that additional consent f study is necessary.	, .	_
Regarding the use of the water sample resu	Its with other research groups:	
You MAY / MAY NOT (circle one) s Division of Drinking Water and the w	• • • • • • •	
You MAY / MAY NOT (circle one) sh and questionnaire responses with the Sciences Center who are studying en	ne researchers at the U.C. Davis	
Signature of Participant	Printed Name	Date

Participant Number	
(for study use only)	