

Attachment 3a: NFR INFORMED CONSENT DOCUMENT

National Firefighter Registry Consent Form

Key Information (Short Summary): The National Firefighter Registry (NFR) is a voluntary registry created to evaluate cancer trends in U.S. firefighters, including career, volunteer, seasonal, wildland, and paid-on-call firefighters. The NFR is administered by the National Institute for Occupational Safety and Health (NIOSH). The NFR tracks the health of its participants over time to evaluate cancer incidence and risk factors associated with firefighting, improve cancer prevention, and conduct public health activities for the benefit of firefighters. If you join the NFR, you will be asked to provide personal, health, lifestyle, and occupational information through a user profile and questionnaire in a secure web portal. Any firefighter can register regardless of health status. You can register in the NFR in 30–45 minutes by completing this consent form and enrollment questionnaire.

If you are diagnosed with cancer in the United States, your cancer will be automatically reported to the population-based cancer registry in the state or territory where you were living at the time of your diagnosis. NIOSH will match the personally identifiable information you provide in the NFR (such as name, date of birth, social security number) with this diagnosis information for the purposes of determining cancer status, cancer diagnosis information, and vital status.

NIOSH may also collect information about your work history (such as fire incidents attended, employment duration, and job titles held) from fire departments, federal or state agencies, or other entities to estimate your exposures. NIOSH will keep all your personal information confidential and protect it to the fullest extent allowed by federal law.

1	Who is administering the NFR?	NIOSH is a federal agency that studies worker safety and health. We are part of the U.S. Centers for Disease Control and Prevention (CDC), a component of the Department of Health and Human Services (HHS).
2	What is the purpose of the NFR?	The NFR aims to better understand the link between firefighting and cancer in the United States, and to equip the fire service and public health communities with knowledge to help them reduce cancer in firefighters. The NFR will also make de-identified data—data with name, address, and other identifying information removed—available, as appropriate, to the public including researchers, firefighters, and national fire service organizations to improve research efforts on cancer incidence among firefighters.
3	Who is eligible for the NFR?	All adult members of the U.S. fire service (18 years of age or older), including active, former, and retired members, who have ever been an active firefighter will be eligible to join the NFR, regardless of whether they have been diagnosed with cancer. This includes career, volunteer, seasonal, wildland, and paid-on-call firefighters.
4	What is expected of me?	After creating an account and signing this consent form, you will be asked to complete a user profile and enrollment questionnaire. The questions focus on basic demographic information, work history and exposures, other job information, health information, and other risk factors for cancer. It is critical that you complete the entire enrollment questionnaire to help NIOSH better understand the link between firefighting and cancer. Once you have registered, NIOSH will be able to track any potential cancer diagnoses using information from your user profile updates, and by

		matching your data to external databases such as population-based, or state, cancer registries. By signing this consent form, you give NIOSH permission to access any potential cancer information from these population-based cancer registries or databases (see Section 6 for more details). We will also send you occasional notifications, reminders, and follow-up questionnaires asking for additional details on your health or work as a firefighter. Follow-up questionnaires are voluntary but important for understanding the relationship between firefighting and health status over time. We may also reach out to fire departments, federal or state agencies, or other entities to learn more about your fire responses such as the number and types of fire incidents attended. This will not require any action from you. If you separately track your exposures or participate in a study related to your occupation as a firefighter, you can request that this information be shared with NIOSH. This will help us understand how your exposures relate to cancer risk.
5	What is the time commitment?	You should be able to read and complete this consent form, a user profile, and the initial questionnaire in 30–45 minutes. All questions are optional, except for name, date of birth, and sex. If you do not have time to complete the questionnaire in one sitting, you can log off and finish it later. Once you finish, you are officially registered with the NFR. Because cancer can take years to develop, the NFR is designed to track cancer diagnoses and evaluate cancer risk factors over a long period of time. To do this, we will regularly send you voluntary but important follow-up questionnaires over time. We will also encourage you to update your NFR user profile whenever there is a change in your work status or assignment, legal name, email, or residential address.
6	Will my personal information be kept private?	Your personal information such as your name, address, or other information that identifies you will be labeled with a code number and stored in a secure place and protected with a password. Only authorized personnel who work with the NFR will know the code and be able to identify you if needed. NIOSH will protect this information to the fullest extent allowed by federal law. Your information will be kept in a system of records (SOR) (09-20-0147) under the Privacy Act of 1974 (Privacy Act), as amended, (5 U.S.C. § 552a). The Privacy Act governs the collection, maintenance, use, and dissemination of information about individuals that is maintained in systems of records (or groups of records) and is retrievable by an identifier, by federal agencies. The Privacy Act prohibits the release of your information maintained in such a system unless you provide written consent, or the disclosure is made under an exception listed in the statute

	or pursuant to a routine use in the SOR. Note, however, that any disclosure permitted by a Privacy Act exception or routine use may be prohibited by the Assurance of Confidentiality, which is further described below. As an additional layer of protection, your identifiable information will be covered by an Assurance of Confidentiality (AoC), as authorized by Section 308(d) of the Public Health Service Act. The purpose of the AoC is to limit the use of your identifiable information to only those purposes necessary for the NFR to fulfill its public health purpose. The AoC provides that identifiable information will be used only for the purposes stated in the AoC, and will not be disclosed or released without your consent. In addition, the AoC provides that none of your identifiable information will be disclosed to any individual or entity that does not have a professional relationship with NIOSH, even after death. All personnel who handle your identifiable information will pledge to follow a strict security and confidentiality protocol, participate in annual security training, and sign a Nondisclosure Agreement and Confidentiality Pledge. For example, under the protection of section 308(d) of the Public Health Service Act: • NIOSH cannot give your identifiable information to consumer advocacy groups. • NIOSH cannot give your identifiable information to your insurance company. • NIOSH cannot be forced to share your identifiable information for a lawsuit. • NIOSH cannot release your identifiable information for use as evidence even if there is a court subpoena. <u>Data linkages for exposure and health outcome information</u> NIOSH may collect specific work history information (such as incidents attended, employment duration, and job titles held) to estimate the number and type of your exposures. To do this, we may need to provide your name, date of birth, organization name, and/or employee ID to federal, state, or fire departments or agencies, or other entities that maintain these records. This information would only be provided to these entities so they can locate your specific occupational exposure history records. No other information would be provided to these entities. NIOSH will also obtain information about your cancer and health status, potential cancer diagnosis, and vital status over time through data linkages to population-based cancer registries and other health outcome databases
--	---

		such as the National Death Index (NDI) of CDC’s National Center for Health Statistics (NCHS). To make these data linkages, NIOSH will need to submit certain pieces of information you provide in the NFR (such as name, date of birth, social security number) to institutions managing external or information databases including population-based cancer registries, NDI, or other health-outcome databases. Your information will be transmitted through a secure mechanism, such as software programs that offer password encryption. NIOSH will maintain the information it acquires from these databases in the NFR. After the linkages have been made, the information that NIOSH provided for making the linkages will be destroyed by the institutions managing the external databases, either by routine protocol or through an agreement with NIOSH. <u>Sharing of de-identified data</u> One of the primary goals of the NFR is to share de-identified health and occupational information with the public, including researchers, firefighters, and national fire service organizations, while protecting your privacy. We will not give your name, address, or any other identifying personal or health information to anyone who is not part of the NFR project without your written permission. If external researchers want to analyze firefighter health and safety using NFR data, they will have to apply for access through the Research Data Center (RDC), an institution dedicated to protecting the confidentiality of survey respondents while providing access to restricted-use data. If a research proposal through the RDC is accepted, NIOSH will remove all directly identifying information (like name, address, social security number) from your record prior to release of select data. These measures will protect your identity while still enabling research on firefighting occupational hazards, cancer incidence within the firefighting population, ways to improve equipment and safety protocols, preventative measures for firefighters, and development of best work practices.
7	Is my participation voluntary?	The NFR is voluntary. No one can force you to register or submit information. If you change your mind and wish to withdraw from the NFR, simply contact NIOSH (NFRRegistry@cdc.gov) and you (and data about you) will be withdrawn from the registry and you will no longer be able to sign into the NFR. Please note, however, that data provided for a specific study or analysis prior to your request cannot be withdrawn.
8	Are there direct benefits to me?	Participants will receive no direct benefits from registering in the NFR. Findings from the NFR, however, may increase scientific understanding of how firefighting exposures relate to cancer.

9	Are there risks associated with participating in the NFR?	You may experience stress from participating in a study focused on cancer. While there is always a risk that data could be accidentally released, we have obtained the highest level of protection allowable for federal data and as provided by federal law. The NFR will minimize any privacy risks by requiring authentication during login, encrypting all data, storing your name and other identifiable information separately from your questionnaire responses or exposure data, and assigning a unique identifier to your personal data. See Section 6 above which explains additional privacy protections.
10	Will I or anyone else receive study results?	Analysis of the NFR data will result in scientific papers and reports. The papers and reports will summarize NIOSH's findings and will never identify you or any other individual. These papers and reports will be provided to the public, fire service organizations and departments. NIOSH will also post any papers and reports on its website (www.cdc.gov/NFR) and make them available to NFR participants.. NIOSH will not release your individual data or individual study results to anyone without your written permission. See Section 6 for more details.
11	Who can I talk to if I have more questions?	Answers to frequently asked questions (FAQs) about the NFR are available at www.cdc.gov/NFR For additional questions, contact the NFR team at NFRRegistry@cdc.gov .
12	Your consent and signature	Regardless of whether you sign this form or register in the NFR, you are not giving away any legal rights or benefits to which you are otherwise entitled, and there will not be any effect on your employment, health care coverage, medical treatment, or insurance benefits. I have read and understand the content of the consent form, and understand what is required to be in the NFR, including how my information will be used and protected. I understand that by agreeing to participate, I will be contacted by the NFR periodically to voluntarily update my information. ☐ I understand what is required of me to be in the NFR and agree to participate in the NFR. ☐ I do not want to participate in the NFR. _____ Participant signature Date