

Attachment 3a. Informed Consent

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. 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.

The NFR tracks the health of its participants. 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. 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. The National Institute for Occupational Safety and Health (NIOSH) will match the information you provide in the NFR with this diagnosis information. NIOSH may also collect information about your work history from your fire department(s) to estimate your exposures. NIOSH will keep all your personal information confidential and protect it to the fullest extent allowed by law. The goal of the NFR is to understand and prevent cancer in the U.S. fire service.

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 National Firefighter Registry (NFR) aims to better understand the link between firefighting and cancer in the United States, and to improve occupation-related cancer prevention for the benefit of firefighters. The NFR will also make de-identified data—data with name, address, and other identifying information removed—available to public health researchers to provide them with comprehensive datasets to improve current 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?	<p>After signing this consent form, you will be asked to confirm your identity while creating an online account, complete a user profile and then fill out an enrollment questionnaire. The questions focus on basic information, work history and exposures, other job information, current health status, and other risk factors for cancer. It is critical that you complete the entire enrollment questionnaire to help us better understand the link between firefighting and cancer.</p> <p>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 population-based, or state, cancer registries. By signing this consent form, you give NIOSH permission to access any potential cancer diagnosis information from these population-based cancer registries.</p> <p>We will also send you occasional notifications, reminders, and follow-up questionnaires asking for additional details on your health or work as a</p>

Public reporting burden of this collection of information is estimated to average 5 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to - CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333 ATTN: PRA (0920-xxxx).

		<p>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 your fire department 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.</p> <p>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.</p>
5	What is the time commitment?	<p>You should be able to read and complete this consent form, your user profile, and the initial questionnaire in 30–45 minutes. You do not have to answer all the questions. 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.</p> <p>Because cancer can take years to develop, the NFR is designed to track cancer diagnoses over a long period of time. To do this, we will send you voluntary but important follow-up questionnaires from time to time over the next few decades, regardless of your cancer status. We will also encourage you to update your NFR user profile whenever there is a change in your work status or assignment, legal name (e.g., marriage), email or mailing address, or cancer status.</p>
6	Will my personal information be kept private?	<p>Your information will be kept in a system of records (09-20-0147) under the Privacy Act of 1974, as amended, (5 U.S.C. § 552a). The Privacy Act prohibits the release of your information unless you provide written consent, or the disclosure is made under an exception listed in the statute. 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 people 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 law. The NFR is covered by an Assurance of Confidentiality (AoC), section 308(d) of the Public Health Service Act, which is the highest level of protection available under federal law.</p> <p>The purpose of the AoC is to prevent the use of your identifiable information for any purpose other than those necessary for the NFR and described in the assurance. All individuals who handle your information will be required to follow a strict security and confidentiality protocol, participate in annual security training, and sign a Nondisclosure Agreement and Confidentiality Pledge. 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, it states that none of your identifiable information will be disclosed to any individual or entity that does not have a professional relationship with CDC/NIOSH, even after death.</p> <p>For example, under current law:</p> <ul style="list-style-type: none"> • 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.

		<ul style="list-style-type: none"> • NIOSH cannot release your identifiable information for use as evidence even if there is a court subpoena. <p>To determine your cancer status, cancer diagnosis information, and vital status over time, the NFR will need to share your information with population-based cancer registries and the National Death Index (NDI) of CDC's National Center for Health Statistics (NCHS). The information obtained from these registries and the NDI will then be maintained in the NFR. Your information will be transmitted through a secure mechanism (e.g., using software programs that offer password encryption) and after linkages have been made, your information will be destroyed by the external information databases, either by routine protocol or an agreement with NIOSH.</p> <p>One of the primary goals of the NFR is to share health and occupational information with public and private researchers, firefighters, and national fire service organizations while protecting your privacy. We will not give your name, address, or any other identifying information to anyone who is not part of the NFR project. If external researchers want to analyze firefighter health and safety using NFR data, they will have to apply for access through a Research Data Center, an institution dedicated to protecting the confidentiality of survey respondents while providing access to restricted-use data. If the proposal is accepted, we will remove any identifying information from your record (making the data de-identified) prior to release, and the data will not include any personally identifying information (e.g., name, address, social security number).</p> <p>These measures will protect your identity while still enabling research on firefighting occupational hazards and cancer or other disease risk. This information may also permit research on improving equipment, enhancing safety protocols and preventative measures for firefighters, and development of best work practices.</p>
7	Is my participation voluntary?	<p>The NFR is voluntary. No one can force you to register.</p> <p>If you change your mind and wish to withdraw from the NFR, simply contact NIOSH (NFRRegistry@cdc.gov) and your data will no longer be used in any analyses and you will no longer be able to sign into the NFR. Please note, however, that de-identified data provided for a specific study or analysis prior to your request cannot be retrieved.</p>
8	Are there direct benefits to me?	<p>You may not personally benefit from participating in the NFR or from the analysis of your de-identified information shared with approved researchers. Findings from the NFR may increase scientific understanding of how firefighting exposures relate to cancer.</p>
9	Are there risks associated with participating in the NFR?	<p>You may experience stress from participating in a study focused on cancer. If you are uncomfortable answering a question, you can skip it.</p> <p>While there is always a risk that data could be accidentally released, we have obtained the highest level of protection allowable for Federal data. The NFR will minimize any privacy risks by requiring authentication during login, encrypting all data, storing your name and other identifiable information separately from</p>

