

National Firefighter Registry: Status Report

National Firefighter Registry Subcommittee

A subcommittee of the NIOSH Board of Scientific Counselors

September 6, 2022

Kenny Fent, PhD, CIH

Lead, National Firefighter Registry (NFR) Program

National Institute for Occupational Safety and Health (NIOSH)



**NATIONAL
FIREFIGHTER
REGISTRY**
Understanding &
Reducing Cancer

The findings and conclusions in this presentation are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention, National Institute for Occupational Safety and Health.

Overview of Project Background and Status

The NFR Science Team

Lead epidemiologist: Miriam Siegel, DrPH

Health scientist: Alex Mayer, MPH

Health scientist: Andrea Wilkinson, MS

Health communications: Greg Hartle (split with Field Research Branch)

Public health advisor: Jasmine Nelson (split with Field Research Branch)



IARC MONOGRAPHS VOL. 132: OCCUPATIONAL EXPOSURE AS A FIREFIGHTER

Occupational exposure as a firefighter is *carcinogenic to humans (Group 1)*

on the basis of *sufficient evidence for cancer in humans*



The IARC Monographs classification indicates the level of certainty that an agent can cause cancer (*hazard identification*)

Higher level of certainty (left) Lower level of certainty (right)

Cancer types with sufficient evidence for cancer in humans:



Genotoxicity



Fire

Strong mechanistic evidence in exposed firefighters



Exposures of firefighters include combustion products, diesel exhaust, building materials, asbestos, chemicals, shift work, ultraviolet radiation

Firefighters respond to various types of



Cancer types with limited evidence for cancer in humans:



Mesothelioma, Bladder cancer

IMPORTANT KNOWLEDGE GAPS

- What is the cancer risk for volunteer firefighters?
- What is the cancer risk for the sub-specialties of the fire service, such as wildland firefighters, fire-cause investigators, industrial firefighters, airport rescue firefighters, and fire instructors?
- How does the cancer risk vary for demographic groups, including women and ethnic and racial minorities?
- How does the cancer risk vary regionally across the U.S. fire service, such as for firefighters who work in more rural areas?
- How prevalent are rare forms of cancer among firefighters?
- How does the cancer risk change with increasing exposures, including major events?
- What other occupational and non-occupational risk factors contribute to cancer risk among firefighters?
- To what extent do different control interventions and workplace practices reduce the risk of cancer?
- Are there other chronic illnesses that are elevated in firefighters?



National Firefighter Registry (NFR)

Mission: To generate detailed knowledge about cancer in the fire service through a voluntary registry that reflects our nation's diverse firefighters.

Vision: To equip the fire service and public health communities with the knowledge they need to reduce cancer in firefighters.

Components:

1. **Collect self-reported information** on workplace & personal characteristics through **web portal**
2. **Obtain records from fire departments or agencies** to track trends and patterns of exposure
3. **Link with health information databases** including population-based cancer registries and the National Death Index to detect cancers and deaths
4. **Make de-identified data available** for external researchers



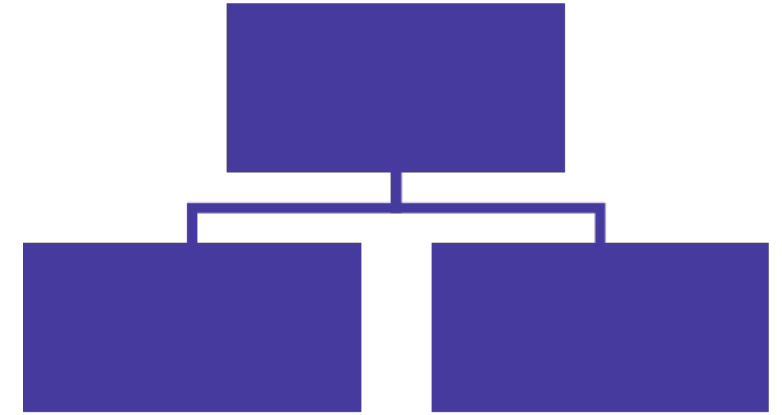
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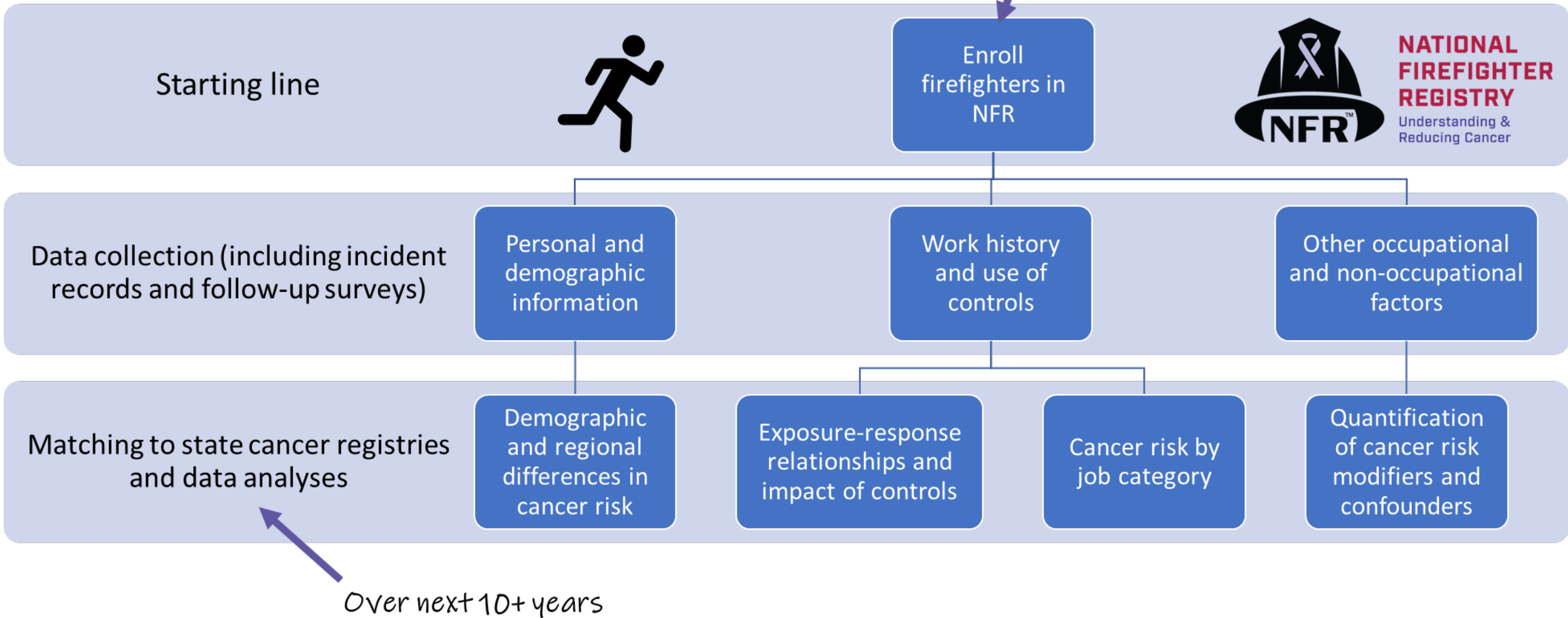
NFR Enrollment Design

Enrollment routes:

- **Open Cohort (non-probability sample)**
 - Any current/former/retired firefighter
 - Beneficial for diverse sample; but may not be generalizable
- **Targeted Cohort (prospective cohort)**
 - Sampling design to recruit *active* FFs from selected fire depts/state agency rosters
 - Focused enrollment of women, minorities, volunteers
 - Access fire department records



NFR Roadmap



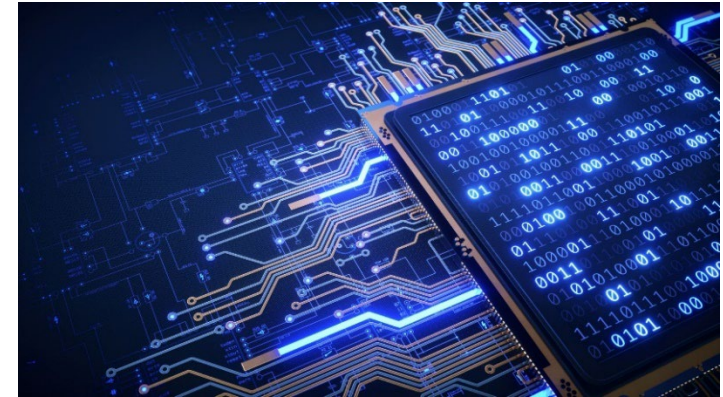
What have we been up to?

- Developing the web portal
- Fine-tuning the enrollment questionnaire
- Obtaining an assurance of confidentiality
- Updating the protocol
- Establishing relationships and keeping fire service informed
- Developing communications materials



Developing the web portal

- **Developed business needs, use cases, and requirements**
 - Based in part on NFRS input (Aug. 2021 meeting), requirements included:
 - Multi-factor authentication (no ID proofing)
 - Editable user profile: name, address, phone, current work status
 - One-way entry enrollment questionnaire: all other questions
 - Last 4 digits of social security number
- **Worked with development team (DevTeam) to implement requirements**
 - Shared working draft of the user profile and enrollment questionnaire
 - DevTeam built wireframes/prototypes
 - Conducted internal testing and provided feedback
 - DevTeam updated web portal based on feedback (repeat) – *Agile development*



Developing the web portal

- **External testing**
 - Web portal hosted publicly in test environment
 - Integrated with the Login.gov sandbox
 - NFR Science Team did more testing
 - Testing with University of Cincinnati IT students
 - Testing with Loveland-Symmes Fire Dept (Ohio) firefighters
- **Preparing web portal for production environment (“live”)**
 - DevTeam is addressing all remaining user experience (UX) issues
 - All security and compliance testing and documentation is being finalized
 - Setting up a help desk (800 number and email)



Loveland Symmes Fire Department

5h · 🌐

Today's shift working with the team from the CDC kicking the tires on the New National Firefighter Cancer Registry. Thanks to Dr. Fent for including LSFD in his testing.



Fine-tuning enrollment questionnaire

- Web portal includes skip patterns and other logic to improve UX
- Testing identified other minor questionnaire issues (e.g., need to add response choices)
- Resulted in a few edits to the questionnaire and user profile
- Submitted a non-substantive change request (CR) to the Office of Management and Budget (OMB) Paperwork Reduction Act (PRA) department
- Obtained CR approval from OMB on **July 19, 2022**:
[National Firefighter Registry - OMB 0920-1348](#)

Obtaining an Assurance of Confidentiality

- **Drafted an Assurance of Confidentiality**
 - Includes details regarding the protection of individual identifiers
 - Also includes mechanism for sharing de-identified data
- **Submitted for review and approval**
 - Includes reviews by CDC Privacy and Confidentiality Unit, Confidentiality Review Group, and Office of General Counsel (OGC)
 - OGC carefully considered the Firefighter Cancer Registry Act of 2018 in their review
 - OGC requested changes to the consent form
 - NFR Science Team addressed all comments
 - Obtained approval on **July 25, 2022**

Updating the protocol

- **A draft protocol was shared with the NFRS (and posted online) on Oct. 29, 2020**
 - This version incorporated feedback from the NFRS report from Aug. 4, 2020
- **Updated protocol – posted to the NFRS website on August 29, 2022**
 - Incorporates changes to the consent form, user profile, and enrollment questionnaire
 - Includes updated security and compliance information
 - Includes updated data sharing details (as reflected in the AoC)
 - Includes cleared communications materials

Establishing relationships and keeping fire service informed

- Identified 8 fire departments who have expressed interest in testing the NFR web portal
 - OH, KY, IN, IL, AZ, VA, MD, CA
- Attended and/or presented at the following conferences:
 - National Fire Cancer Symposium
 - International Association of Arson Investigators (IAAI) Conference
 - Washington State Council of Firefighters Conference
 - Women in Fire Conference
 - Fire Department Instructors Conference, FDIC (first ever NFR booth)
 - National Volunteer Fire Council (NVFC) Training Summit
 - Fire Rescue International, FRI (booth)



Developing communications materials

- Conducted focus groups to test messaging
- Recommended messages:
 - Stand together. Join the NFR.
 - Answer the call. Join your brothers and sisters in a new effort to understand and reduce cancer.
 - Let's leave the fire service better than we found it. Join the NFR.

Characteristic	Total Sample (N=42)
Firefighter Subgroups¹	NA
Female Firefighters	14 (33%)
Firefighters of Color	7 (17%)
Career and Paid-on-Call Firefighters	10 (24%)
Volunteer Firefighters	9 (21%)
Subspecialty Firefighters	3 (7%)
Chiefs and Stakeholders	7 (17%)
Age² (N=35)	
Mean	44 years
Under 30	5 (14%)
Over 30	30 (86%)
U.S. Census Region	
Northeast	8 (19%)
South	17 (41%)

Characteristic	Total Sample (N=42)
Midwest	8 (19%)
West	9 (21%)
Race / Ethnicity^{1,2} (N=35)	NA
Black / African American	2 (6%)
Asian American / Native Hawaiian / Pacific Islander	2 (6%)
American Indian / Alaska Native	2 (6%)
White	27 (77%)
Prefer not to answer	2 (6%)
Hispanic or Latino	3 (9%)
Not Hispanic or Latino	32 (91%)

Footnotes:

¹ Potential overlap between categories. Total may exceed 100%.

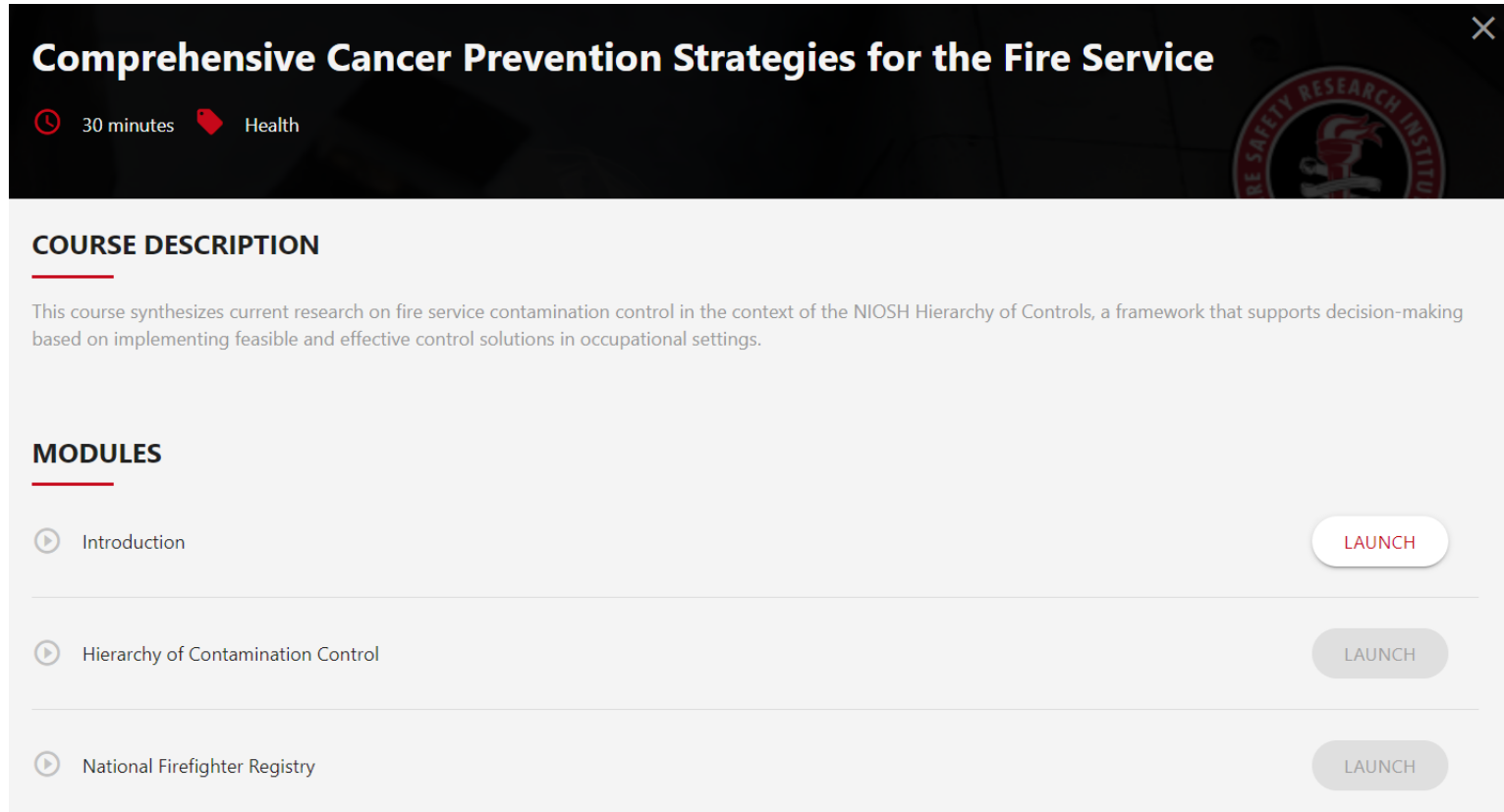
² We did not collect age or race/ethnicity data for the Chiefs and Stakeholder subgroups (n=7). The total N for these categories is N=35 as a result.

Developing communications materials

- Quarterly newsletter (1,490 subscribers)
- NFR brochure
- NFR fact sheet
- Videos: *What is the NFR* and *How the NFR works*
- Conference booth and handouts (balls, clips, carabiners, flashlights)
- Other products in development
 - Social media images and messages
 - Posters and ads (for fire service magazines)
 - Roll call announcement
 - Videos: *How will the NFR protect my data* and *Firefighter testimonials*

Underwriter Laboratories' Fire Safety Academy (FSA) Course

- Ultimate goal is to reduce cancer risk
- FSA has >70,000 accounts and growing
- Includes module on the NFR with link to the website



The screenshot shows a course interface with a dark header. The title is 'Comprehensive Cancer Prevention Strategies for the Fire Service'. Below the title, it indicates a duration of '30 minutes' and a category of 'Health'. A logo for 'Fire Safety Research Institute' is visible in the top right corner. The main content area is white and contains a 'COURSE DESCRIPTION' section with a red underline, followed by a paragraph of text. Below this is a 'MODULES' section, also with a red underline, listing three modules: 'Introduction', 'Hierarchy of Contamination Control', and 'National Firefighter Registry'. Each module has a play button icon and a 'LAUNCH' button to its right. The 'LAUNCH' button for the first module is highlighted in red, while the others are greyed out.

Comprehensive Cancer Prevention Strategies for the Fire Service

30 minutes Health

COURSE DESCRIPTION

This course synthesizes current research on fire service contamination control in the context of the NIOSH Hierarchy of Controls, a framework that supports decision-making based on implementing feasible and effective control solutions in occupational settings.

MODULES

- ▶ Introduction [LAUNCH](#)
- ▶ Hierarchy of Contamination Control [LAUNCH](#)
- ▶ National Firefighter Registry [LAUNCH](#)

Questions?

Demo of the NFR web portal

- <https://nfrtest.cdc.gov>
- Demo by Alex Mayer

Question for Subcommittee

- **What improvements should be considered to enhance the user experience of the enrollment system?**

Rollout and next steps

- **Soft launch: web portal into production (NFR.cdc.gov)**
 - Perform additional testing with firefighters
 - Data will be collected and maintained – firefighters will be enrolling
 - Any issues will be documented and addressed in future releases
- **Slowly ramp up promotion with big push in January**
 - January is Firefighter Cancer Awareness Month
 - This allows for:
 - Organic distribution
 - Further testing/fine-tuning of the enrollment system
 - Developing additional communications materials
 - Coordination with professional organizations, advocacy groups, and trade magazines (ads)
- **Identify fire departments to participate in targeted enrollment**

Current NFR web site

- www.cdc.gov/NFR
- Demo by Kenny Fent

Cleared communications materials

NFR brochure

What is the National Firefighter Registry?

The National Firefighter Registry (NFR) is a voluntary registry of firefighters that is designed to help us better understand cancer in the U.S. fire service.

Congress mandated the NFR's creation through the Firefighter Cancer Registry Act of 2018. The National Institute for Occupational Safety and Health (NIOSH) is leading this effort with input from the scientific and firefighting communities.

“Our goal is to better understand the link between workplace exposures and cancer among firefighters.”

How will the NFR benefit firefighters?

Past studies show that firefighters have increased rates of certain cancers. However, these studies have not determined:

- Cancer rates among volunteer, female, or minority firefighters; or among sub-specialties, such as fire instructors
- How different exposures affect cancer rates
- If certain groups of firefighters have higher rates of cancer based on types and level of exposure, geography, sex, or other traits
- If certain protective measures are associated with reduced rates of cancer

Our ultimate goal is to identify ways to reduce cancer rates among firefighters.

When will NFR registration begin?

We plan to begin registration in 2022. When more details on registration are available we will share them widely through firefighter channels, and update our materials.

What else should I know about the NFR?

- Participation in the NFR is voluntary.
- Registration will take place through a secure web portal and will take around 30 minutes.
- Your personal information will be kept confidential and will not be shared without your permission.
- The NFR is a long-term project that will include important follow-up questionnaires.
- Continued participation in the NFR could help firefighters. The more we know about cancer in the fire service, the more we can do to prevent it.

Firefighters do not need to have cancer or any other health condition to participate in the NFR.



Photo by ebsouth/Getty Images

Who will be included in the NFR?

The NFR will be open to all U.S. firefighters regardless of whether they have a previous cancer diagnosis. We encourage all firefighters to participate in the NFR, including:

- Active, former, and retired firefighters
- Career, paid-on-call, and volunteer firefighters
- Structural firefighters
- Wildland firefighters
- Industrial firefighters
- Military firefighters
- Instructors
- Fire investigators
- Other fire service members

Having many types of firefighters in the NFR is crucial to examining relationships between firefighting activities and cancer.

More information

For more information, please visit www.cdc.gov/NFR, where you can sign up for the NFR newsletter for updates. If you have any questions, please email us at NFRRegistry@cdc.gov.

Photo by ©Jupiterimages/Getty Images



Photo by NFRRegistry/Getty Images

Learn more about the NFR at www.cdc.gov/NFR

If you have questions, please contact NFRRegistry@cdc.gov



Get More Information

Find NIOSH products and get answers to workplace safety and health questions:

1-800-CDC-INFO (1-800-232-4636)

TTY: 1-888-232-6348

CDC/NIOSH INFO: cdc.gov/info | cdc.gov/niosh

Monthly NIOSH eNews: cdc.gov/niosh/eNews

DHHS (NIOSH) Publication No. 2021-115

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May 2021



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Photo by the International Association of Firefighters



Centers for Disease Control
and Prevention
National Institute for Occupational
Safety and Health

NFR Fact Sheet

STAND TOGETHER JOIN THE NATIONAL FIREFIGHTER REGISTRY

Answer the call. Join your brothers and sisters in a new effort to understand and reduce cancer.

What is NIOSH?

The National Institute for Occupational Safety and Health (NIOSH) is the part of the Centers for Disease Control and Prevention (CDC) responsible for conducting research and making recommendations to reduce workplace illness and injury. NIOSH has a long history of working with the fire service and is committed to firefighter health and safety through investigating line of duty deaths, job hazards, cancer and other illnesses.

What is the National Firefighter Registry (NFR)?

The NFR is the largest existing effort undertaken to understand and reduce cancer among U.S. firefighters. In 2018, Congress passed the Firefighter Cancer Registry Act. This Act directed NIOSH to develop a voluntary registry of firefighters to better understand the link between firefighting and cancer.

Why was the NFR created?

Studies have shown that firefighters may have a greater risk for some types of cancer due to their exposure to smoke and hazardous chemicals on the fireground. Many of these studies did not include volunteer firefighters or enough women or firefighters from some racial and ethnic groups to make strong conclusions about their cancer risk. The NFR will include members of these groups to better understand the connection between firefighting activities and cancer among all U.S. firefighters.

WHO CAN REGISTER FOR THE NFR?

All U.S. firefighters, with or without cancer, no matter their length of service. This includes:

- Active and retired firefighters
- Career, paid-on-call, and volunteer firefighters
- Structural firefighters
- Wildland firefighters
- Instructors
- Fire investigators
- Other fire service members

Having all types of firefighters join the NFR is vital to examining the relationship between firefighting and cancer. Participation is voluntary.

How do I join?

Registration will take place through a secure website and will take about 30 minutes. When joining, you will provide information about yourself – name, date of birth, and some basic information about your work exposures, health, and lifestyle.

NATIONAL FIREFIGHTER REGISTRY

Why should I join?

The more we know about cancer, the more we can do to prevent it. By joining the NFR, you can:

- Help protect the next generation of firefighters from cancer
- Pave the way for new safety measures to protect your brothers and sisters in the fire service
- Help protect firefighter families and their communities from experiencing the impact of cancer on their loved ones
- Improve our understanding of cancer risk among female firefighters, volunteer firefighters, and firefighters who are Black or African American, Hispanic or Latino, Asian, American Indian or Alaska Native, or from other racial and ethnic groups that have been underrepresented in research

How does the NFR work?

Every time someone is diagnosed with cancer, details about their cancer are reported to the cancer registry in their state, but detailed information about their work is not captured. By providing information about themselves and their work, NFR participants will allow NIOSH researchers to match NFR information with cancer diagnosis information to better understand cancer and its risk factors in the fire service.

Do NFR participants need to contact NIOSH if they are diagnosed with cancer?

No. NIOSH will be able to track information related to cancer by linking information on individual firefighters enrolled in the NFR with state cancer registries. Firefighters should consult with their doctor if they have any concerns about their health.

What if I don't have cancer, can I still join?

Yes. All firefighters, with or without cancer, are encouraged to join the NFR, and their participation is critical for understanding firefighters' risk of cancer.

What information do I need to provide and how will it be protected?

When you sign up for the NFR, you will be asked for your name and other identifying information (e.g., date of birth), as well as details about your work as a firefighter. Privacy and data security are top priorities for the NFR. Firefighters join the NFR through a secure website using multi-factor authentication. Firefighter data is stored securely with multiple layers of encryption. Your identifiable information will be kept confidential and only accessible to NIOSH researchers.

What happens after I join?

Because the NFR is a long-term project, NIOSH researchers may reach out to you about once a year with voluntary, but important follow-up questionnaires. Your continued participation is key to protecting firefighter health.

When can I join?

The NFR will open to all U.S. firefighters later this year.



SUBSCRIBE TO THE
NFR QUARTERLY
NEWSLETTER FOR THE
LATEST NFR UPDATES.

LEARN MORE AT [CDC.GOV/NFR](https://www.cdc.gov/nfr)



NFR Quarterly Newsletter

NIOSH



**NATIONAL
FIREFIGHTER
REGISTRY**

Understanding &
Reducing Cancer

Quarterly Newsletter

Spring/Summer 2022

Welcome from the National Firefighter Registry Team Lead



Greetings from NIOSH,

It's hard to believe that summer is here. We are feeling the heat outside and the heat to get the National Firefighter Registry (NFR) up and running. We are currently testing and fine-tuning the enrollment system while making sure it's user-friendly and highly secure. We are still on target to launch the NFR enrollment system this fall.

Although not directly related to the NFR, I just finished participating in the [International Agency for Research on Cancer](#) workgroup meeting to evaluate the carcinogenicity of the firefighting occupation. The meeting was a very rigorous process (with work that began a year ago) and involved experts all over the world. It was one of the most rewarding activities I've been involved in during my career. After thoroughly reviewing the available scientific literature, the working group classified occupational exposure as a firefighter as *carcinogenic to humans* (Group 1), on the basis of *sufficient evidence* for cancer in humans ([IARC Monographs evaluate the carcinogenicity of occupational exposure as a firefighter – IARC \(who.int\)](#)). The full evaluation will be published in 2023.

Read on for more information about other accomplishments by the NFR team. Stay connected with the NFR by visiting www.cdc.gov/NFR. Please stay safe and well. We look forward to seeing or hearing from you in the future.

Kind Regards,

Kenny Fent, PhD, CIH
CDR, USPHS
Research Industrial Hygienist/Team Lead
National Firefighter Registry Program
Centers for Disease Control and Prevention
National Institute for Occupational Safety and Health

International Association of Arson Investigators (IAAI) Conference

On April 13, Alex Mayer represented the NFR team at the International Association of Arson Investigators Conference in Jacksonville, Florida. This conference provides a space for arson investigators to network, advocate, and educate others on

Strength Through Diversity

DRAFT

**For All Firefighters.
All Backgrounds.
All Experiences.**

Learn More About the
National Firefighter Registry at
www.cdc.gov/NFR

October 2021

**3... 2... 1...
LAUNCH**

DRAFT

**The First National Effort
to Monitor Cancer in
Firefighters is Here!**

Learn More About the
National Firefighter Registry at
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October 2021

CANCER

HERE, USE
THIS LINE!

DRAFT

**Join your brothers and sisters
in a new effort to understand
and reduce cancer.**

www.cdc.gov/NFR

October 2021

Communications materials in development

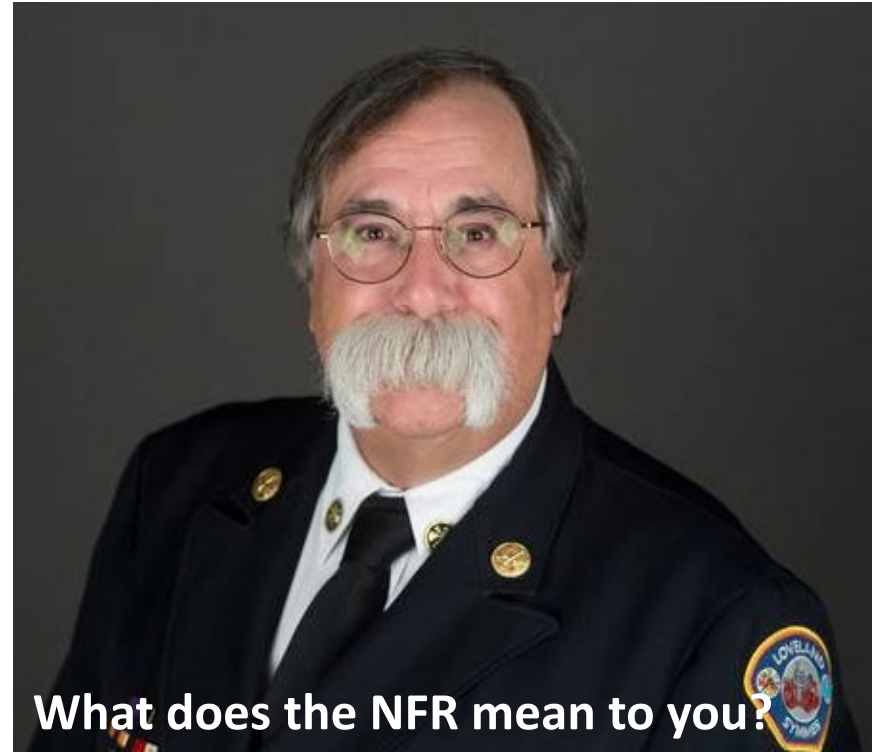
Artwork by Paul Combs



Communications materials in development

Palm cards and posters

How will the
National Firefighter Registry
protect my data?



Videos in development

Data security video and firefighter testimonial videos



Conference exhibit booth

Upcoming conferences and meetings

- **Urban Fire Forum (Metro Chiefs)**
- **North American Fire Training Directors Conference (booth)**
- **NFFF Life Safety Summit**
- **Firehouse Expo (booth)**
- **U.S. Fire Administration (USFA) meetings**
- **International Association of Fire Chiefs (IAFC), Symposium in the Sun**
- **Brothers Helping Brothers, Firefighter Health & Wellness Conference**
- **International Association of Fire Fighters (IAFF) - Affiliate Leadership and Training Conference**
- **Wildland Urban Interface Conference**
- **Congressional Fire Service Institute (CFSI) Symposium**
- **Many others**

Fire service SME support (sub-contracts)

- **Experts will help us make connections with specific groups of firefighters and will assist with disseminating information and reviewing materials as needed**
 - **Craig Haigh – retired fire chief and fire instructor**
 - Will serve as a spokesperson at conferences and connections with fire chiefs and instructors
 - **Rick Swan – retired wildland firefighter, retired IAFF official,**
 - Will help with connections to wildland fire agencies and IAFF local sections
 - **Rick Markley – volunteer firefighter and fire investigator, former editor-in-chief of Fire Rescue 1 and Fire Chief**
 - Will help with connections to volunteer firefighters/organizations
 - **John Oates – former fire chief, CEO of non-profit International Public Safety Data Institute**
 - Will help with connections to east coast fire departments and provide critical reviews
- ***Others will be considered***

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Questions for Subcommittee

- **What is the best way to get this information into the hands of the fire service?**
- **How can we best build trust with departments to encourage participation in both open enrollment and targeted enrollment where records may be requested?**