

# The National Firefighter Registry (NFR) for Cancer *Progress Update*

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**NATIONAL  
FIREFIGHTER  
REGISTRY**  
*for Cancer*  
Understanding &  
Reducing Cancer

# NFR for Cancer

**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 <https://NFR.cdc.gov>
  - *Takes about 30 minutes to enroll*
2. **Obtain records from fire departments or agencies** to track trends and patterns of exposure
3. **Link with health information databases** including state cancer databases
4. **Make de-identified data available** for external researchers

# NFR Subcommittee Overview

- Subcommittee of the NIOSH BSC
- Comprised of 11 rotating experts and 2 co-chairs that provide guidance to the NFR project team
- Required to meet, at minimum, once per calendar year
- Subcommittee is charged with advising NIOSH Director on:
  - Increasing awareness of the NFR and encouraging participation
  - Consideration of unique data collection needs
  - Methods to encourage participation in general and from minority, female, and volunteer firefighters
  - How information will be submitted to the NFR
  - How information will be stored and accessed
  - How information about firefighters will be maintained and updated over time
  - Methods for estimating number of fire incidents attended by a firefighter and type of fire incidents

# Last NFR Subcommittee Meeting

- Met in person June 13, 2023
- Provided an updated protocol (see [NFRS webpage](#))
- Summarized the progress made over the last year
- Discussed and obtained feedback in three topic areas:
  1. Communications campaign
  2. Targeted enrollment plans
  3. Future follow-up questionnaires

# Progress over the last year









- Made finishing touches to the enrollment questionnaire
- Finalized the Assurance of Confidentiality
- Updated our website: [www.cdc.gov/NFR](http://www.cdc.gov/NFR)
- Obtained written support from several fire service organizations
- Performed user acceptance testing for the NFR web portal: <https://NFR.cdc.gov>
- Conducted soft rollout of the web portal at 7 fire departments
- Created and staffed the NFR Help Desk
- Launched the NFR nationally in April 2023
- Rolled out our comprehensive communications plan

# Supporting Organizations

[Print](#)

This mission of the National Firefighter Registry (NFR) for Cancer is to generate detailed knowledge about cancer in the fire service through a voluntary registry that reflects our nation's diverse firefighters. The following organizations have provided official support for the mission of the NFR.

## Written support:

- International Association of Fire Fighters (IAFF): [IAFF Letter of Support](#) 
- National Volunteer Fire Council (NVFC): [NVFC Position Statement Supporting the National Firefighter Registry](#)  
- International Association of Fire Chiefs (IAFC): [IAFC Letter of Support](#) 
- Urban Fire Forum of the Metropolitan Fire Chiefs: [2022 Urban Fire Forum Position Statement – Support for the National Firefighter Registry](#) 
- Center for Public Safety Excellence (CPSE): [CPSE Letter of Support](#) 
- National Fallen Firefighters Foundation (NFFF): [NFFF Letter of Support](#) 
- North American Fire Training Directors (NAFTD): [NAFTD Letter of Support](#)  
- Fire Department Safety Officers Association (FDSOA): [FDSOA Support for the National Firefighter Registry \(NFR\)](#)  
- Firefighter Cancer Support Network (FCSN): [FCSN Letter of Support](#) 
- Underwriters Laboratories (UL), Fire Safety Research Institute (FSRI): [FSRI Letter of Support](#) 
- Women in Fire: [Women in Fire Letter of Support](#) 
- Women's Fire Alliance (WFA): [WFA Letter of Support](#) 
- National Association of Hispanic Firefighters (NAHFF): [NAHFF December 2022 President's Report](#) 
- International Association of Wildland Fire (IAWF): [IAWF Letter of Support](#) 
- International Association of Arson Investigators (IAAI): [IAAI Position Statement](#) 
- Science to the Station, a Health and Wellness Alliance: [Letter of Support](#) 
- NDRI-USA: [Letter of Support](#) 

## Financial support:



U.S. Fire Administration  
Working for a fire-safe America

18 Organizations  
as of February 2024

# User testing and soft rollout

- End of 2022 – conducted internal user testing, data validation, and fine-tuning of the web portal
- Start of 2023 – pushed web portal to production and conducted soft rollout with firefighters at 7 fire departments:
  1. Loveland-Symmes FD, Ohio
  2. Independence Fire District, Kentucky
  3. Tucson FD, Arizona
  4. Pike Township FD, Indiana
  5. Fairfax County Fire & Rescue, Virginia
  6. Howard County Fire & Rescue, Maryland
  7. Hanover Park FD, Illinois



Kenny Fent hands a thank you plaque to Executive Officer Bruck Hawk at Loveland-Symmes Fire Department. (Photo by NIOSH)

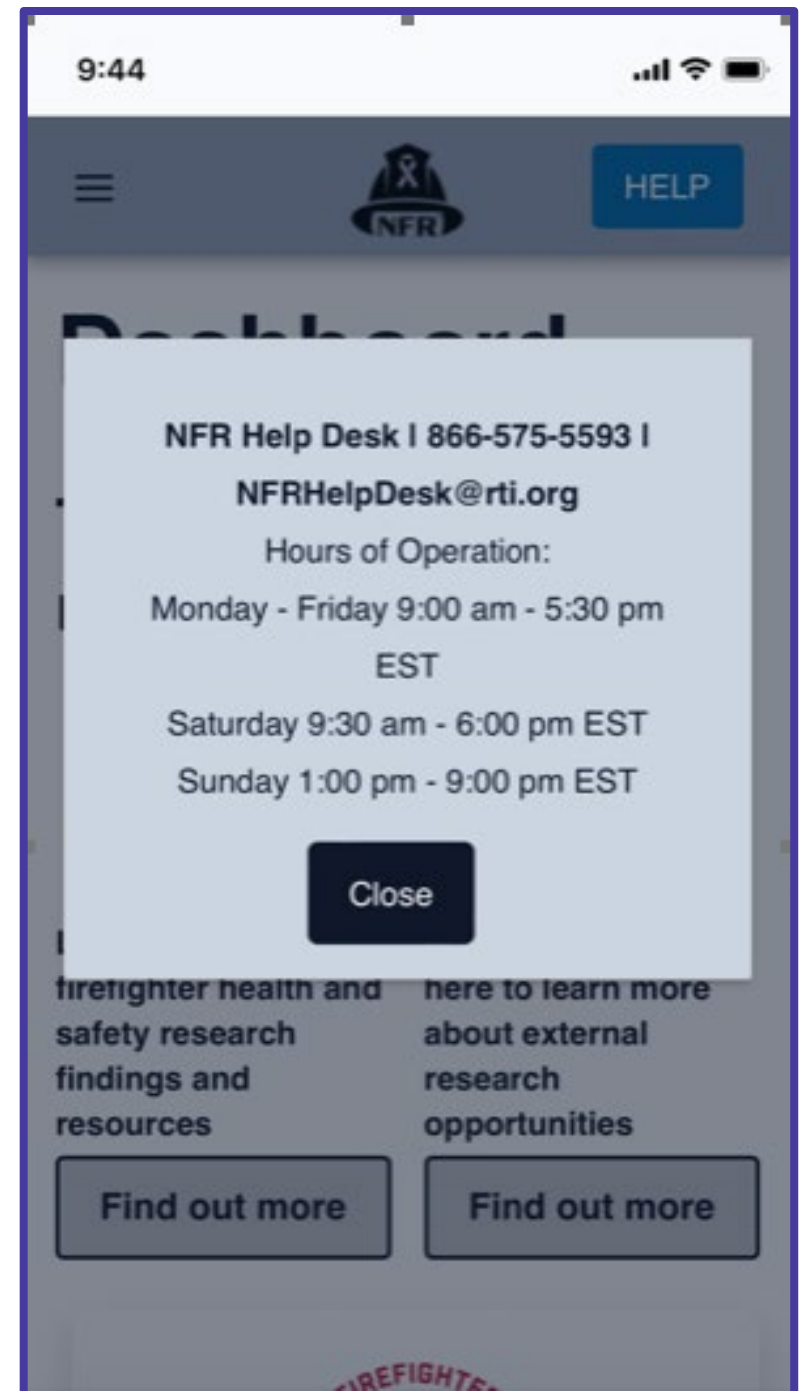
# **Final updates to the web portal**

- **Obtained feedback from firefighters during soft rollout and from select firefighters who enrolled at the Fire Department Safety Officers Association (FDSOA) Conference in Florida in January**
- **Implemented final changes and pushed that version to production in April 2023**
- **Notified fire service partners through our Newsletter on April 13**
- **Press release and social media campaign on April 17**
- **Big announcement at the Fire Department Instructors Conference (FDIC) on April 27**



# NFR help desk

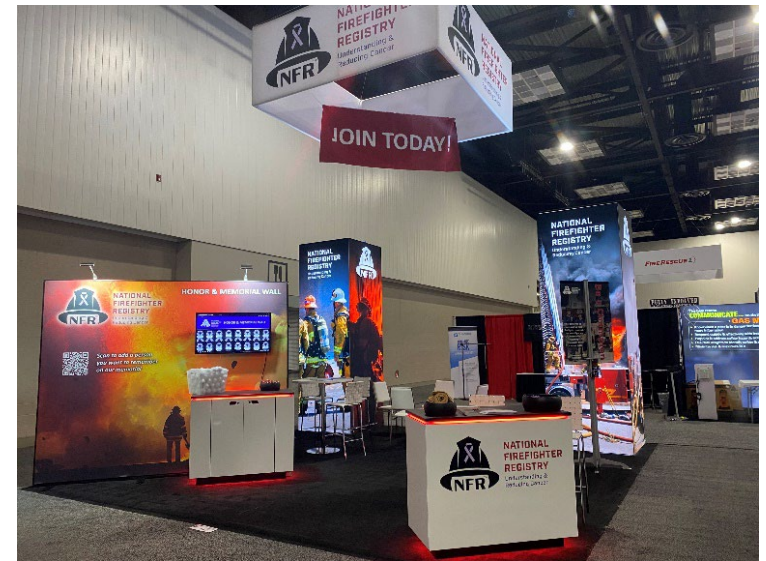
- Staffed by Contractor
- Ticketing process for resolving technical issues
- Response within 24 hours



# NFR announcement at FDIC 2023

- Opening ceremony on Thursday April 27
- Attended by thousands in-person and thousands virtually
- Kenny Fent joined on stage by representatives at IAFF, FCSN, NFFF, and FDIC
- Exhibit booth open on Thursday – Saturday
  - Collected >350 emails
  - Distributed >1500 printed materials and >3500 branded items
  - > 2000 people accessed the web portal during the week of FDIC

IAFF = International Association of Fire Fighters, FCSN = Firefighter Cancer Support Network, NFFF = National Fallen Firefighters Foundation, FDIC = Fire Department Instructors Conference



Photos by NIOSH

# Other communication activities since launch

- Updated the NFR web portal to make it more user friendly
  - Removed feature that prevented editing previous responses in the work history section
  - Added new feature that provides an **NFR participant number**
- Set up exhibit booths and presented at conferences across the country
- Worked closely with fire service partners to deliver messaging via social media posts, videos, ads, and podcasts
  - >5M social media impressions, >100K video views, >125K visits to NFR websites



NATIONAL  
FIREFIGHTER  
REGISTRY  
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Confirm eligibility and then click "Login.gov" below to create account or sign in.

I am at least 18 years of age \*

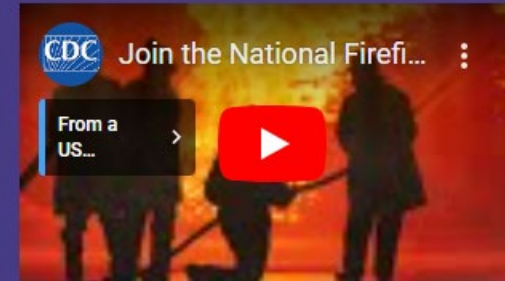
I have served or am currently serving as a US firefighter \*

Login.gov

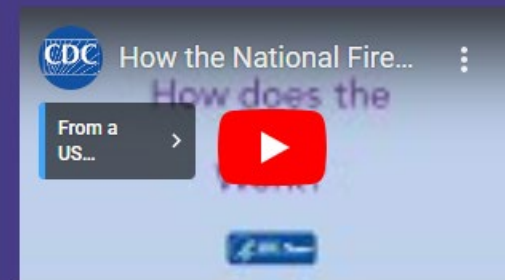
Want more information? Visit [our website](#)

Need help signing up? View our [Tip Sheet](#)

Watch our videos below to learn more.

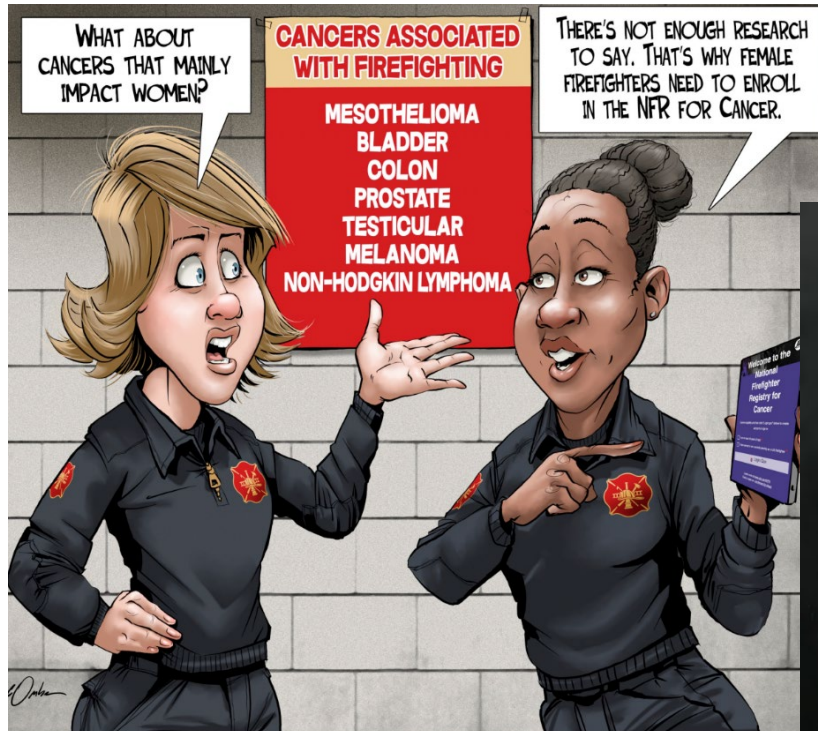


Join the NFR for Cancer - hear fire service members share why joining the NFR is important.



How does the NFR for Cancer work? - learn how the NFR will help researchers investigate the link between firefighting and cancer.

# Specific audiences



Learn More About the  
National Firefighter Registry (NFR) for Cancer  
at [www.CDC.gov/NFR](http://www.CDC.gov/NFR)

## Women

## Wildland

**NATIONAL FIREFIGHTER REGISTRY**  
Identifying & Reducing Cancer

# STAND TOGETHER

Join your brothers and sisters in a new effort to understand and reduce cancer. Together, we can have a lasting impact on the fire service.

JOIN THE NATIONAL FIREFIGHTER REGISTRY

[NFR.CDC.GOV](http://NFR.CDC.GOV)

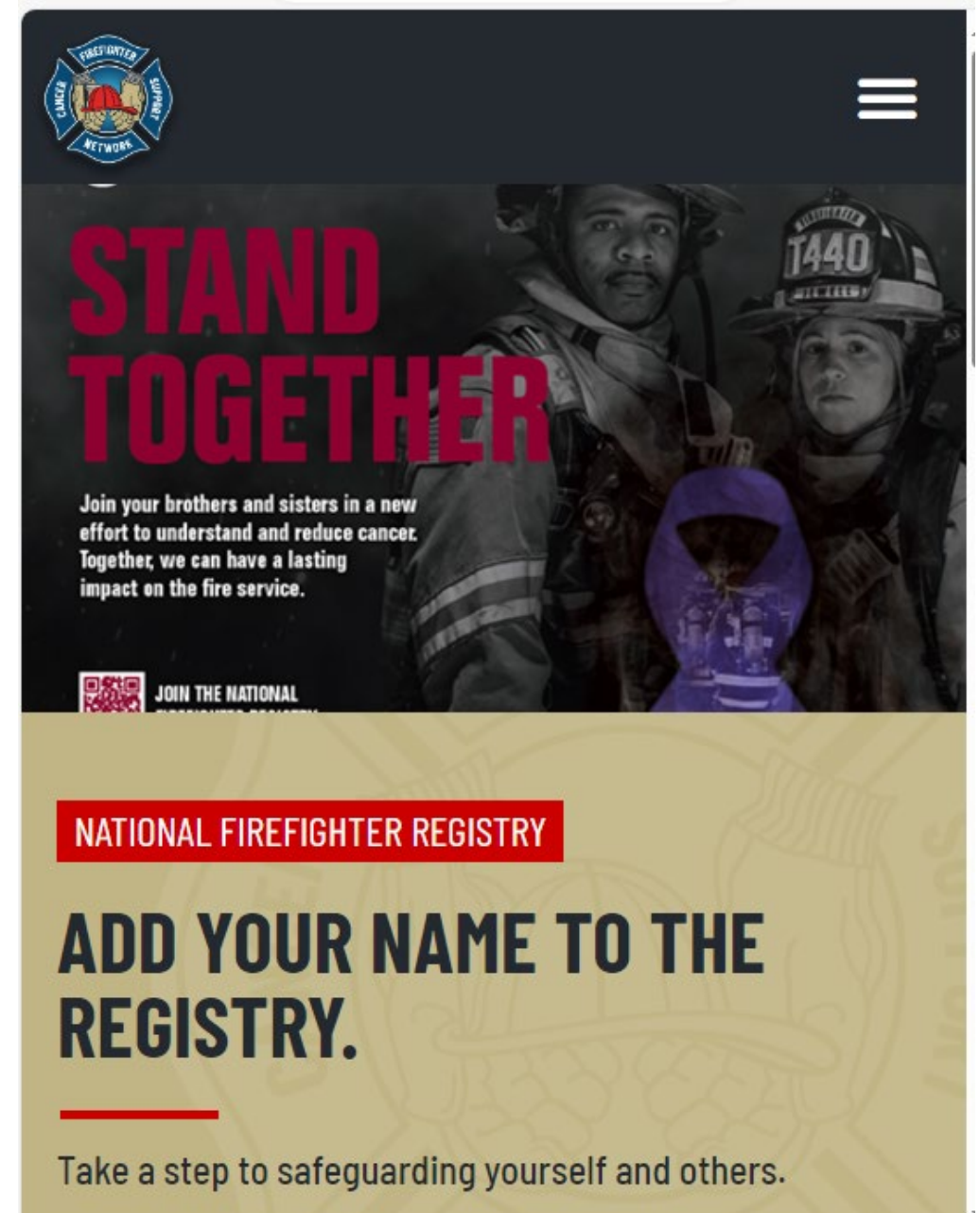
DHHS (NIOSH) Publication No. 2023-111  
DOI: <https://doi.org/10.26616/NIOSH-PUB2023111>  
March 2023



## Other populations under-represented in research

# Firefighter Cancer Awareness Month (FFCAM)

- FFCAM (January 2024)
  - NIOSH worked closely with Firefighter Cancer Support Network (FCSN) and International Association of Fire Fighters (IAFF) to promote the importance of the NFR
  - A variety of communications were released throughout the month
  - Witness a large increase in participation



The graphic features a dark background with a photograph of two firefighters. One firefighter is wearing a helmet with the number '1440'. A purple awareness ribbon is prominently displayed in the foreground. The text 'STAND TOGETHER' is written in large, bold, red letters. Below this, a message reads: 'Join your brothers and sisters in a new effort to understand and reduce cancer. Together, we can have a lasting impact on the fire service.' A QR code is located in the bottom left corner, with the text 'JOIN THE NATIONAL' next to it. At the top left is the Firefighter Cancer Support Network logo, and at the top right is a hamburger menu icon.

**STAND TOGETHER**

Join your brothers and sisters in a new effort to understand and reduce cancer. Together, we can have a lasting impact on the fire service.

JOIN THE NATIONAL

**NATIONAL FIREFIGHTER REGISTRY**

**ADD YOUR NAME TO THE REGISTRY.**

Take a step to safeguarding yourself and others.

Example of promotion by partner (FCSN)

# Discussion topics with NFR Subcommittee

\* Conversation facilitated by NFRS Co-Chairs, Grace LeMasters and Pat Morrison

- **Who are we missing in our marketing?**
- **How do you feel our initial launch is going?**
  - **What could be improved?**
- **Do you think our current messaging is effective?**
  - **How could our messaging be refined?**

## Feedback

- **To boost enrollment, consider conducting more outreach through state and local organizations.**
  - **Examples include state governor's offices, state fire marshals, state fire academies, state fire associations, state fire chiefs' associations, state associations of cities and towns, and city managers associations**

## Progress

- **Presented at the Michigan Fire Marshal's monthly meeting (November 2023)**
- **Formed a working relationship with the NY Department of Homeland Security Emergency Services (DHSES)**
  - **Providing information about the NFR during their statewide trainings**
- **Actively pursuing relationships with other state fire marshals**
- **Obtained support from the North American Fire Training Directors (NAFTD)**
  - **Several state training directors are providing information about the NFR (including QR code linking to the NFR web portal) to training academy students**



# Targeted Enrollment Plans



# Original Design

- Select fire departments
- Collect detailed rosters and contact information
  - Name, email address, phone number, residential address
- Reach out to firefighters on the rosters
- Track participation rates on an individual-level
- Request incident/employment records for those who enrolled



**Feedback  
from  
Departments**

➤ **Hesitancy or inability to share roster records (some or all variables)**

- Privacy and legal concerns for many depts
- Depend on culture and geographic location of dept
- Require heavy proactive messaging & education to/from dept leadership
- Likewise for incident/employment records

➤ **Preference for having leadership disseminate invitations**

- Belief that participation would be higher if messaging from dept
- Emails from NIOSH might be distrusted or disregarded

# Alternative Design

- Develop recruitment procedure for dept leadership
  - With initial & follow-up emails to send to their own rosters
- Obtain workforce count (i.e., denominator) from dept
  - Request demographic denominators for stratified participation rates
- NIOSH *estimate* participation rates
  - Feedback loop to dept leadership to facilitate reminders to enroll
- Explore incident/employment records with dept leadership at later date
  - Closely follow the U.S. Fire Administration (USFA) update to the Incident Reporting System

# Discussion topics with NFR Subcommittee

\* Conversation facilitated by NFRS Co-Chairs, Grace LeMasters and Pat Morrison

- **What are the thoughts on original vs. alternative design for targeted enrollment?**

## Feedback

- A few members stated that the alternative approach is likely to be successful, particularly in collaboration with department and state leaders
- Other members recommended that NIOSH explore additional options before making a decision, such as a hybrid approach, a pilot test, or leveraging state cancer registries even further

## Progress

- Explored other options
- Held additional calls with fire department leadership and scientific partners regarding feasibility of roster sharing
- Decided to proceed with the **alternative design**, but to leave open the option of collecting more detailed roster information in the future
- Identified initial list of possible fire departments for targeted enrollment

# Follow-Up Questionnaires



# Purpose of Follow-Up Questionnaires

- **Add to our current knowledge base on “specialty topics”**
  - Major events or deployment activities, special health topics, topics for specific groups, emerging issues
- **Collect self-reported longitudinal information**
  - Changes in workplace exposures over time
- **Important considerations:**
  - Follow-up participation is also voluntary
  - Comprehensive, prospective cancer follow-up done through state cancer registry linkages

# Potential Topics

## Longitudinal work information

- Dept/position/work status changes?
  - Protective practices?
- Incident response estimates?

## Lifestyle

- Smoking detail/changes?
- Alcohol use detail/changes?
  - Diet?

## Health/Co-Morbidities

- Reproductive?
- Behavioral/mental?
- Attitudes, beliefs, perceptions?

## Subspecialties

- Wildland, Wildland urban interface (WUI)?
  - Women?
  - Volunteers?
  - Major events?



# Discussion topics with NFR Subcommittee

\* Conversation facilitated by NFRS Co-Chairs, Grace LeMasters and Pat Morrison

- **What is the ideal length for follow-up questionnaires?**
- **What topics should be prioritized?**
  - In light of likely loss to follow-up and survey brevity, how to prioritize questions on self-reported longitudinal information/changes in exposure over time versus “specialty” topics?
- **What is the best timeline for sending follow-up questionnaires?**
  - Modules provided all at once in web portal as they become available and/or notifications sent periodically (with some groups being skipped some years)?
  - Ascertaining longitudinal information: questions based on “since last survey response” versus “in the last year” (for example)?

## Feedback

- Follow-up questionnaires may need to be short and no more than once per year
- Consider administering questionnaires at the same time for all participants
- It might be beneficial for follow-up questionnaires to coincide with events such as Firefighter Cancer Awareness Month
- Some questionnaire space may be devoted to updates on work information until the new USFA Incident Recording System is up and running
- Consider sharing NFR data with firefighters when asking them to complete questionnaire
  - “Give something when you ask for something”

## Progress

- Committed to keeping the follow-up questionnaires short
- Plan to issue at the same time for all participants, and no more than once per year
- Still working on the content and following USFA progress
- Open to sharing findings annually when requesting participation in follow-up questionnaires

# Thank you!



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For more information: [www.cdc.gov/NFR](http://www.cdc.gov/NFR)

*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.*