The National Firefighter Registry (NFR)

National Firefighter Registry Subcommittee Meeting
May 15, 2020

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National Firefighter Registry
Understanding and Preventing Cancer

Coming soon...

LEARN MORE AT: www.cdc.gov/NFR
Introduction & Background

Dr. Kenny Fent
Why is the NFR being created?

- The Firefighter Cancer Registry Act of 2018
- Previous studies, including a study by NIOSH, indicate that firefighters are at higher risk of cancer.
- Studies are limited by small numbers of women and minorities, and a lack of data on volunteers.
- No national data sources exist that combine exposure and cancer information with which to study the link in firefighters.
- NFR goal is to track firefighters’ cancer risk over time to better understand the link between workplace exposures and cancer.
Who will be included?

- The NFR will represent ALL firefighters, not just those with cancer
- Minority, female, and volunteer firefighters
- Also interested in sub-specialties like:
  - Instructors
  - Wildland firefighters
  - Arson investigators
- Goal is to enroll 200,000+
What will registration look like?

- Registration web-portal under development:
  - Secure (two-factor authentication)
  - Require informed consent
- Collected information will include:
  - Demographics (name, age, sex, etc.)
  - Work history / exposures
  - Use of control measures
  - Other risk factors
- Important, voluntary follow-up questionnaires
- **Personal information will be kept in accordance with strict Federal privacy laws**
How will cancer risk be determined?

- Link participants to state/federal records using individual identifiers over time
  - State cancer registries
    - Databases of all cancer diagnoses
    - NFR participants won’t need to contact NIOSH if they develop cancer
    - Used to determine cancer incidence
  - National Death Index
    - National database of deaths and causes of deaths
    - Used to determine cancer mortality
What will the NFR address?

- How much cancer/what types of cancers among firefighters?
- How does cancer risk vary:
  - Among different groups of firefighters
  - With use of control interventions
  - Geographically
  - With increasing exposures, including major events
- What are the current workplace practices being employed?
What will happen with the findings?

- Disseminate findings
  - Scientific & trade publications
  - Communications to the fire service, policy-makers, and the public
  - De-identified (i.e., maintaining privacy) data available for researchers

- Findings will inform:
  - Interventions, training, practices, and policies
  - Awareness among firefighters, fire departments & agencies, policy-makers, professional associations, healthcare providers, friends and family

- Reducing occupational cancer for firefighters is the long-term goal of the NFR
NFR National Firefighter Registry Timeline

- Establish the National Firefighter Registry
- Recruit and enroll firefighters
- Collect data
- Analyze and disseminate results

2020

2021-2023

2024+
Recruitment
NFR Participants

Targeted Cohort:
Currently active firefighters from selected fire departments or states

Open Cohort:
Any members of the U.S. fire service, including active, former, and retired members, who have ever been an active firefighter (paid or volunteer)
NFR Participants

Targeted Cohort:
Currently active firefighters from selected fire departments or states

- Provides the population at risk required for assessing cancer incidence rates
- Reduces selection/participation bias
- Additional exposure information from department records
- Ability to assess response characteristics and comparisons with Open Cohort
- Most cost/labor/time-intensive
- Excludes non-structural, non-active firefighters

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Open Cohort:
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- Non-probability sample for which all firefighters are eligible
- Best method for recruiting a large, diverse, & inclusive sample
- Less cost/labor/time-intensive
- Opportunity for earlier analyses internal to sample (e.g., descriptive, cross-sectional, case-control)
- Subject to selection/participation bias
- Limited to self-reported exposure information
Targeted Cohort: Currently active firefighters from selected fire departments or states

Fire department sampling

State firefighter certification records
Targeted Cohort: Currently active firefighters from selected fire departments or states

Fire department sampling

Phase 1: Focused enrollment of women, minorities, & volunteers

Phase 2: Stratified random sample

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Fire department sampling

Phase 1: Focused enrollment of women, minorities, & volunteers
- Stakeholder- and census-identified departments with large female / minority workforces
- Stakeholder- and census-identified departments with large volunteer workforce

Phase 2: Stratified random sample

Geographic Units
1 2 3 4

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Stakeholder- and census-identified departments with large volunteer workforce

Phase 2: Stratified random sample

Geographic Units

1 2 3 4

Tier 1: Career (>100) - Pop. >100k - Pop <100k

Tier 2: Volunteer

Geographic Units

1 2 3 4 5 6 7 8 9
Targeted Cohort Sample Size Estimates

Minimum benchmarks:

>1,000 women; >6,500 non-white firefighters; >5,000 volunteers
to detect elevations in breast or all cancers in comparison to the general population (SIRs)
Open Cohort:
Any members of the U.S. fire service, including active, former, and retired members, who have ever been an active firefighter (paid or volunteer)

- Wildland
- Arson investigators
- Federal
- Structural
- Instructors
- Airport rescue
- Other sub-specialties

Web portal enrollment
Potential prospective sub-cohorts:
Departments or other memberships with high participation from active rosters (denominator info needed) to be analyzed as part of the Targeted Cohort

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Arson investigators
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Structural
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Other sub-specialties

Web portal enrollment

Potential incident records collection
Open Cohort:
Any members of the U.S. fire service, including active, former, and retired members, who have ever been an active firefighter (paid or volunteer).

Disseminate materials through depts, stakeholders, membership orgs, social media, trade lit.

Presentations at professional conferences and meetings.

Booths at professional conferences where FFs can obtain info/register.

Potential prospective sub-cohorts:
Departments or other memberships with high participation from active rosters (denominator info needed) to be analyzed as part of the Targeted Cohort.

Potential incident records collection.

Recruitment Strategies
Enrollment
TARGETED COHORT
Current firefighters from selected fire depts or state certification records

NFR Enrollment
Primary source of self-reported exposure information

OPEN COHORT
Any current/former members of the U.S. fire service
End results of participation

1.a TARGETED COHORT
Current firefighters from selected fire depts or state certification records

1.b OPEN COHORT
Any current/former members of the U.S. fire service

NFR Enrollment
Primary source of self-reported exposure information

NIOSH periodically links participant information with:
- State cancer registries
- National Death Index/Social Security Admin
  Death Master File

NIOSH administers periodic web portal follow-up questionnaires

NIOSH sends periodic continued engagement communications

NIOSH solicits department employment records for participants (when applicable)

NIOSH links with exposure tracking data for participants (when applicable)
TARGETED COHORT
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OPEN COHORT
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Individual FFs consent & enroll through web portal

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**TARGETED COHORT**
Current firefighters from selected fire depts or state certification records

- Rosters & incident records don’t have to be sent together, but rosters with contact information are essential here.
- Rosters for all current fire personnel sent to NIOSH (include names, contact info only)
- Dept. incident records sent to NIOSH when available (incident records dating back to 2010 or earlier)

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FFs have already enrolled in NFR through web portal

NIOSH actively recruits individual FFs

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**OPEN COHORT**
Any current/former members of the U.S. fire service

**1.**
- Individual FFs consent & enroll through web portal

**2.a**
- NIOSH actively recruits individual FFs
- FFs have already enrolled in NFR through web portal

**2.b**
- Dept. incident records sent to NIOSH when available (incident records dating back to 2010 or earlier)

**3.a**
- Individual FFs consent & enroll through web portal
- NIOSH administers periodic web portal follow-up questionnaires

**3.b**
- NIOSH actively recruits individual FFs
- NIOSH sends periodic continued engagement communications
- NIOSH solicits department employment records for participants (when applicable)

**4.a**
- Individual FFs do not consent / do not respond
- NIOSH links with exposure tracking data for participants (when applicable)

**4.b**
- NIOSH does not use any of individual FFs’ information

**5.a**
- NIOSH periodically links participant information with:
  - State cancer registries
  - National Death Index/Social Security Admin Death Master File

**5.b**
- NIOSH sends periodic continued engagement communications
- NIOSH solicits department employment records for participants (when applicable)
**TARGETED COHORT**
Current firefighters from selected fire depts or state certification records

Rosters & incident records don’t have to be sent together, but rosters with contact information are essential here.

Rosters for all current fire personnel sent to NIOSH (include names, contact info only)
Dept. incident records sent to NIOSH when available (incident records dating back to 2010 or earlier)

FFs have already enrolled in NFR through web portal
NIOSH actively recruits individual FFs

**OPEN COHORT**
Any current/former members of the U.S. fire service

Individual FFs consent & enroll through web portal

Process repeated every ~2-3 years for updated incidents & recruiting new FFs since last date records were shared

NIOSH periodically links participant information with:
- State cancer registries
- National Death Index/Social Security Admin
- Death Master File

NIOSH administers periodic web portal follow-up questionnaires
NIOSH sends periodic continued engagement communications
NIOSH solicits department employment records for participants (when applicable)
NIOSH links with exposure tracking data for participants (when applicable)

Rosters & incident records don’t have to be sent together, but rosters with contact information are essential here.

Individual FFs do **not** consent / do **not** respond

NIOSH does **not** use any of individual FFs’ information
Potential Limitations & Considerations

- Generalizability may be impacted by:
  - Participation bias
  - Small sample sizes (e.g., rare cancer, small subgroups, etc.)

- Analyses may be affected by:
  - Record availability
  - Self-report of past exposures
  - Healthy worker bias
  - Long latency of cancer
Data Sharing

Alex Mayer
Review the Law

- Firefighter Cancer Registry Act of 2018 stipulates NIOSH:
  - Make data publicly available
  - Protect firefighters’ privacy
- Obtain an Assurance of Confidentiality (AoC)
  - An AoC is the highest level of protection allowed by the federal government
  - Protects individuals and institutions
Assurance of Confidentiality (AoC)

- Uses for data:
  1. Monitor trends in cancer incidence among the U.S. fire service
  2. Secondary purposes related to non-cancer research aims
  3. Approved secondary research purposes proposed by external investigators and collaborators
Data sharing

- Developing a plan for sharing data
- One option: Research Data Center (RDC)
  - A proposal to the RDC
  - Reviewed by the RDC, NIOSH, and state cancer registries
  - (If approved) the appropriate data files will be provided to the RDC for analysis
Re-contacting participants

- External researchers can solicit NFR participants for their interest in an outside study
- NIOSH will review and approve requests
- Once NIOSH has approved the proposal, the NFR program will be responsible for re-contacting participants
Communication Plan

Will Wepsala
Communication Goals

- Raise awareness of the NFR
- Clarify the scope of the NFR
- Highlight the need for the NFR
- Encourage firefighters to sign up
- Encourage firefighters to share information with each other
Communication Tools

- Focus groups and/or online surveys
- Social media
- Publications
- Videos
- Conferences
- Newsletter
- NFR Website: www.cdc.gov/NFR
- NFRS Website: https://www.cdc.gov/niosh/bsc/nfrs/default.html
Enrollment Questionnaire

Andrea Wilkinson
Goals

- Enroll 200,000 firefighters from diverse sample
- Balance brevity with scientific reasoning
- Simple process
- Easily accessible
  - mobile and desktop version
- Secure format
  - Multifactor authentication
- Relevant to all firefighters
  - Current, retired, specialty groups
Enrollment Process

- Step 1
  - Create login.gov account
- Step 2
  - Review and sign informed consent
- Step 3
  - Create user profile
- Step 4
  - Complete enrollment questionnaire
Sign in

Email address

Password

Next

If this is your first time on login.gov, you'll need to click "Create Account"

Secure your account

login.gov makes sure you can access your account by adding a second layer of security.

Select an option to secure your account:

- **Text message / SMS**
  Get your security code via text message / SMS

- **Phone call**
  Get your security code via phone call

- **Authentication application**
  Set up an authentication application to get your security code without providing a phone number

- **Security key**
  Use a security key to secure your account

- **Government employees**
  Use your PIV/CAC card to secure your account

- **Backup Codes**
  Receive a pre-generated list of security codes to use when signing in

Continue
Questionnaire Arrangement

- **User Profile**
  - Basic demographics
  - Some skip patterns and auto-populated fields will come from this information
    - e.g., Male vs female reproductive history questions and employment history
  - Can be easily updated over time to adjust employment status, address, etc.
  - Will lead directly into enrollment questionnaire
Identity Verification

- Social security number
  - Why do we need this?
    - Cancer registry & vital status matching
  - Appropriate timing within questionnaire to ask for SSN?
    - Link with “why are we asking this”
    - Pop-up at end reiterating the importance of gathering SSN
Pilot Testing & Reviews

- 10 fire service professionals from various ranks and backgrounds
  - Average completion time for enrollment questionnaire ~12 minutes
- Questionnaire reviewed by three physicians, two survey methodologists, and numerous epidemiologists
- Feedback
  - Largely positive
  - Incorporated language and organization suggestions
    - e.g., language changes to make questions more relevant to specific groups of firefighters, reordering of questions, grouping of response options, etc.
NIOSH - National Firefighter Registry
Predicting outcomes and improving the life of first responders.

Learn More
Introducing the National Firefighter Registry

Improve data collection, track, and predict the incidence of cancer among firefighters nationwide.

Develop reliable methods for estimating the number and type of fire incidents attended by a firefighter.

Examine cancer risk among recent firefighters exposed to burning of synthetic materials present in newer structures.

Get Started
STEP 1 of 4
Enter your email address

Email
bill@murray.com

Sign Up

STEP 2 of 4
Confirm Your Email Address

An email was sent to confirm your account. To continue, please check your email.

An email will be sent to the user asking them to confirm their account/email address.
Click here to simulate clicking confirm in the email

STEP 3 of 4
Set a Password

Your account has been successfully confirmed. Please set a password.

Password
Crowd

Confirm Password
Crowd

Set Password

Your password has been set.

Register / Enroll
National Firefighter Registry Consent Form

Who is conducting the Registry?
The National Firefighter Registry (NFR) is conducted by the National Institute for Occupational Safety and Health (NIOSH) at the Centers for Disease Control and Prevention (CDC) in Atlanta, Georgia.

What is the purpose of the Registry?
The purpose of the Registry is to collect information about firefighters and individuals who may be at higher risk for certain types of cancer.

Who is eligible for the Registry?
All current and former firefighters in the United States are eligible for the Registry.

Is my participation voluntary?
Yes, participation is voluntary. You can choose not to participate at any time.

What is expected of me?
After enrolling in the Registry, you will be asked to complete a self-administered questionnaire that includes information about your work history, health status, and other relevant factors.

What is the time commitment?
The time commitment is minimal. You will be asked to complete the questionnaire once, at the beginning of the study.

Are there direct benefits to me?
Yes, you may receive a report on the results of the study, which may include information that could be of interest to you.

Are there risks associated with participating in the Registry?
There are no risks associated with participating in the Registry.

What if I am injured or harmed?
It is unlikely that you will be injured or harmed as a result of participating in the Registry.

Will I or anyone else receive study results?
The results of the Registry will be reported to the public, but your individual information will not be disclosed.

Who can I talk to if I have more questions?
For more information, please contact the NFR team at NFRRegistry@cdc.gov.
Thank you!

We sincerely thank you for participating in this important project. Your registration has been submitted to the National Firefighter Registry. Gathering this information is the first step in understanding and preventing cancer in the U.S. fire service.
Questionnaire Discussion
Questions for Input

Dr. Paul Middendorf
The Program Would Like Input on These Questions

I. Communication and Enrollment Issues
1. What are the most effective routes for communicating the enrollment process, data security and confidentiality, and why the NFR program needs access to certain types of records?
2. What are the barriers to participation and what can NIOSH do to increase participation? What is the best process for recruiting states that require firefighter certifications?
3. Should NIOSH implement eligibility criteria for the fire department sampling frame?

II. Science Issues
4. What is the best way to estimate lifetime exposures and changes in implementation of controls over time as a firefighter? What role should follow-on or repeat questionnaires, or department-level surveys, play in this data collection?
5. What other important variables related to cancer risk should be collected as part of the enrollment process and what should be included in follow-on surveys (e.g., lifestyle factors and secondary jobs)? Please keep in mind we would like to limit the time burden on participating firefighters for the initial enrollment process to 30 minutes or less.
6. Are any crucial details missing from the protocol or consent form that would be needed for linking with population-based (i.e., state and territorial) cancer registries? How soon after initial enrollment should NIOSH seek to conduct cancer registry linkages nationally?
7. There was no mention of pilot testing either section of the approach such as recruitment or the questionnaire; are there plans for pilot testing?

8. Has there been a decision regarding implementing the targeted or open cohorts simultaneously or consecutively?

9. Are there data indicating that you will be able to recruit ~40,000 FF/year, and what is the expected split between the targeted and open cohorts?
Thank you!

Website: www.cdc.gov/NFR
Email: NFRegistry@cdc.gov

For more information, contact CDC
1-800-CDC-INFO (232-4636)

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.