The National Firefighter Registry
Progress Update

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Urban Fire Forum
September 22, 2021
National Firefighter Registry (NFR)

Firefighter Cancer Registry Act of 2018:

CDC/NIOSH “to develop and maintain... a voluntary registry of firefighters to collect relevant health and occupational information... for purposes of determining cancer incidence.”
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.

**Protocol objectives**

1. **Collect self-reported information** on workplace & personal characteristics through online 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
Who will be included?

• The NFR will be open to **ALL** firefighters, not just those with cancer
• Voluntary participation
• Emphasis on women, minorities, and volunteers
• Also interested in sub-specialties like:
  • Instructors
  • Wildland firefighters
  • Fire investigators
• Goal is to enroll 200,000+
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 dept/state agency rosters
    - Focused enrollment of women, minorities, volunteers
  - Access fire department records
**NFR Enrollment System (Web Portal)**

*Under development*

- Time-intensive: Data security is top priority; several new Federal security requirements
- Critical that we get this right the first time
- Enrollment will involve:
  1. Informed consent
  2. User profile
  3. Enrollment Questionnaire
     - Demographics, work/exposure history, workplace practices, lifestyle, health history

*Enrollment is expected to take 30-45 minutes*

*In the future, there will be opportunities to take follow-up surveys*
Health Outcome Linkages

Link participants to state/federal records using individual identifiers periodically over time

- **Population-based cancer registries**
  - All states & territories (firefighters protect all parts of the country!)
  - NAACCR’s Virtual Pooled Registry (VPR-CLS)
  - Used to determine cancer incidence

- **National Death Index**
  - National database of deaths and causes of deaths
  - Used to determine cancer mortality

NAACCR = North American Association of Central Cancer Registries
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NFR [Exposure] Data

Web portal

Dept records

Exposure tracking

Cancer registries

Natl Death Index

Health Outcome Linkages
National Firefighter Registry Subcommittee (NFRS) virtual meeting, August 2021

- Federal advisory committee of fire service & scientific experts
  - Previously reviewed & made recommendations for protocol
- NIOSH IT presentation on data security, status, & timeline
  - Mid-2022 anticipated implementation
- Discussion of web registration-related obstacles & suggestions
  - Re-accessing data for user experience vs. identity proofing impact on participation
  - Social security number for data linkages vs. impact on participation
- Public meeting; meeting minutes to be available online

www.cdc.gov/niosh/bsc/nfrs/
Data Sharing & Collaboration

Firefighter Cancer Registry Act stipulates...

- Protect firefighters’ privacy
  - Obtain an Assurance of Confidentiality (AoC)
    - Highest level of protection
- Make data publicly available
  - De-identified
  - Secure mechanism for sharing (i.e., Research Data Center)
NFR Analyses

• 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 current workplace & lifestyle behaviors among firefighters?

• Data quality analyses (e.g., self-report vs. cancer registry information)
Potential Limitations

- Generalizability may be impacted by:
  - Selection/participation bias
  - Small sample sizes (e.g., among specific subgroups of firefighters)

- Analyses may be affected by:
  - Record availability
  - Self-report of past exposures
  - Healthy worker/survivor effects
  - Long latency of cancer
Progress & Timeline

- NFRS reviewed the protocol, consent form, and enrollment questionnaire – posted to the web
- Submitted questionnaire for Office of Management & Budget (OMB) review
- Developed communication materials (brochure, video)
- Drafted an Assurance of Confidentiality (AoC) and submitted for CDC review
- Applying for SSN collection and storage
- Began planning/development of enrollment system and database
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Acknowledgements
Kenny Fent (Team Lead)
Andrea Wilkinson
Alex Mayer
Will Wepsala

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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.