

The National Firefighter Registry

Progress Update

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NIOSH Board of Scientific Counselors
October 5, 2021



**NATIONAL
FIREFIGHTER
REGISTRY**
Understanding &
Reducing Cancer

National Firefighter Registry (NFR)

One Hundred Fifteenth Congress
of the
United States of America

AT THE SECOND SESSION

*Begun and held at the City of Washington on Wednesday,
the third day of January, two thousand and eighteen*

An Act

To require the Secretary of Health and Human Services to develop a voluntary registry to collect data on cancer incidence among firefighters.

*Be it enacted by the Senate and House of Representatives of
the United States of America in Congress assembled,*

SECTION 1. SHORT TITLE.

This Act may be cited as the Firefighter Cancer Registry Act of 2018.

SEC. 2. VOLUNTARY REGISTRY FOR FIREFIGHTER CANCER INCIDENCE.

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.



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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 monitor cancers and deaths

Who will be included?

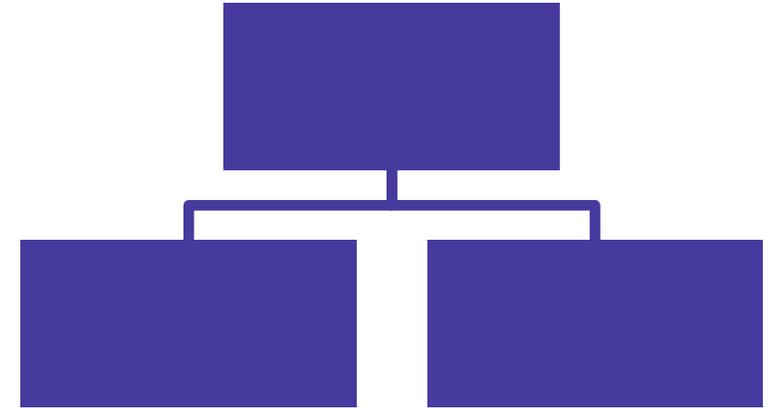
- The NFR will be open to ALL firefighters, not just those with cancer
- Voluntary participation
- Emphasis on women, minorities, and volunteers
- Also interested in sub-specialties like:
 - Instructors
 - Wildland firefighters
 - Fire investigators
- Goal is to enroll 200,000+



NFR Enrollment Design

Enrollment routes:

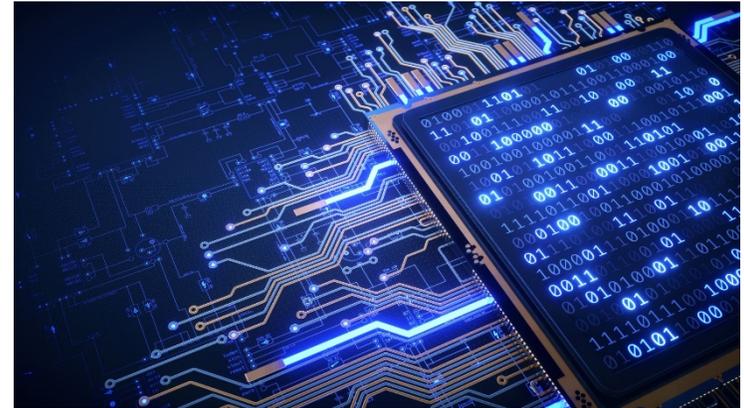
- **Open Cohort (non-probability sample)**
 - Any current/former/retired firefighter
 - Beneficial for diverse sample; but may not be generalizable
- **Targeted Cohort (prospective cohort)**
 - Sampling design to recruit *active* FFs from selected fire depts/state agencies
 - Focused enrollment of women,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



NFR Enrollment System (Web Portal)

Under development

- This is taking the longest time because data security is top priority and there are several new Federal security requirements
- Critical that we get this right the first time
- Enrollment will involve:
 1. Informed consent
 2. User profile/information
 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**

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Supplemental exposure data:

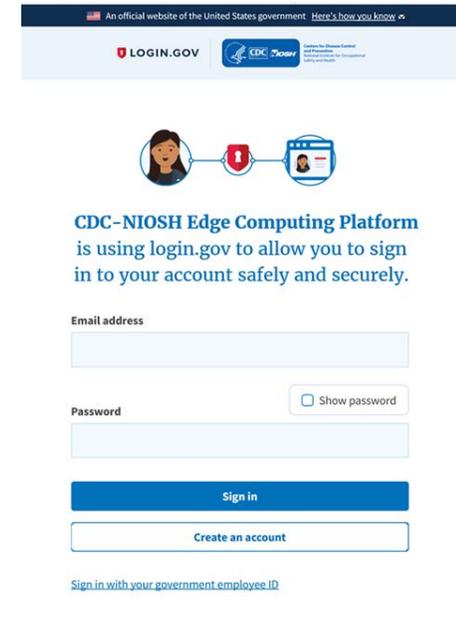
- Fire dept records
- Exposure tracking apps

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

NFR Web Portal Login Process Options

1. Full Registration – No Limits on Data Retrieval/Update
 - Robust participant profile includes employment and health history
 - Participant can view and update previously submitted survey data
 - Requires account creation, multifactored authentication, and **identity proofing**
2. Light Registration – No Retrievable Sensitive Health Information
 - Profile only includes less-sensitive identifiers (name, address, phone, etc.)
 - No ability of participant to retrieve survey responses (sensitive health information)
 - Requires account creation and multifactored authentication
3. No Registration or Profile
 - Functions like a web-based survey
 - No persistent data – each survey is a stand-alone transaction
 - No participant account



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NFR Subcommittee Meeting (Aug. 13, 2021)

- **General public: 3 oral comments and 7 written comments – many regarding the importance of keeping the process simple**
- **NFRS expressed serious concerns about identity proofing hurting participation rates and producing selection bias**
- **Suggested that Option 2 (Light Registration) was a good balance of collecting the information that is needed for the scientific analysis and making some data retrievable for participants without creating substantial obstacles for participation**
- **Full transcripts and meeting notes available at <https://www.cdc.gov/niosh/bsc/nfrs/default.html>**

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



Health Outcome Linkages

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

Social Security Number

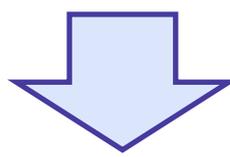
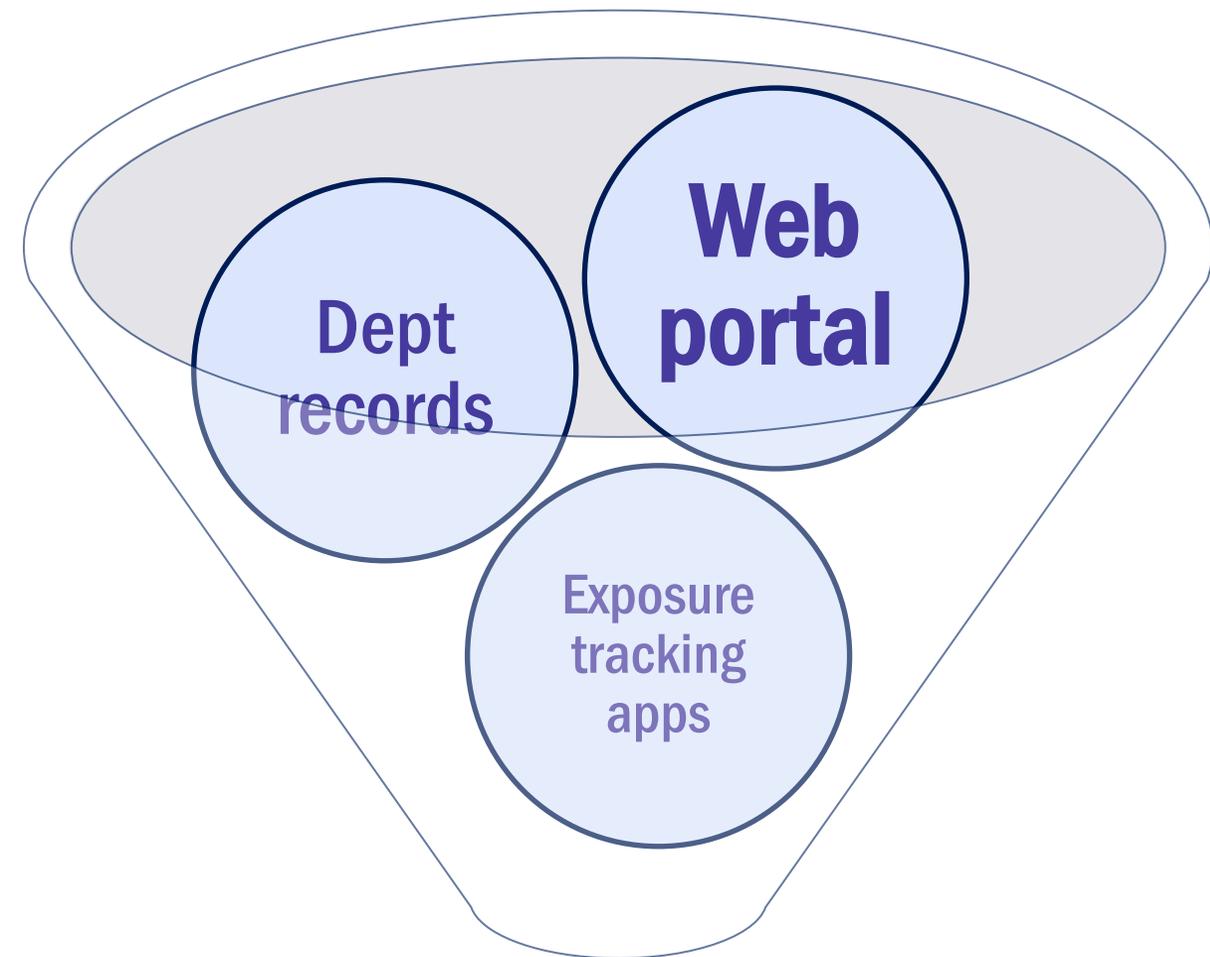
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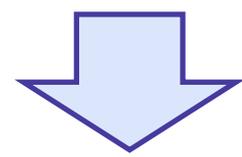
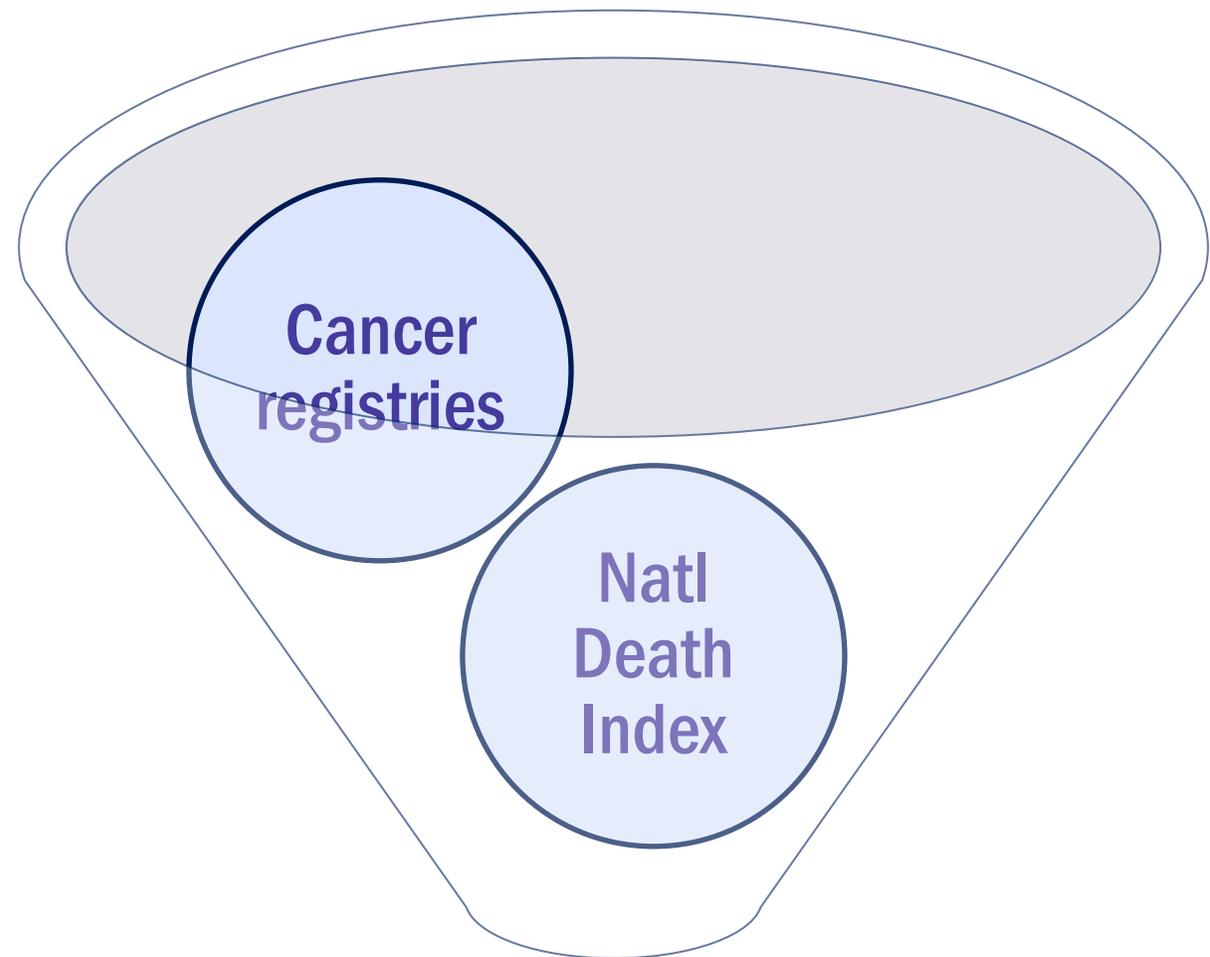
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NFR [Exposure] Data

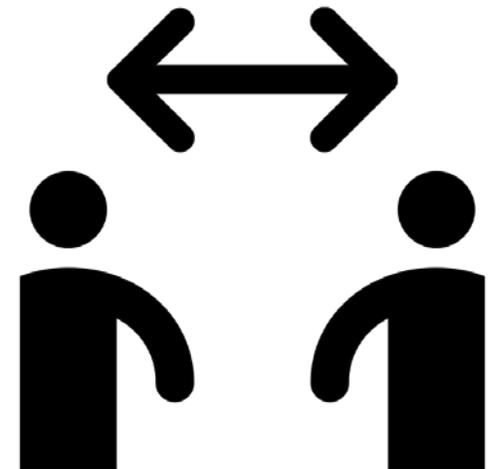


Health Outcome Linkages

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)

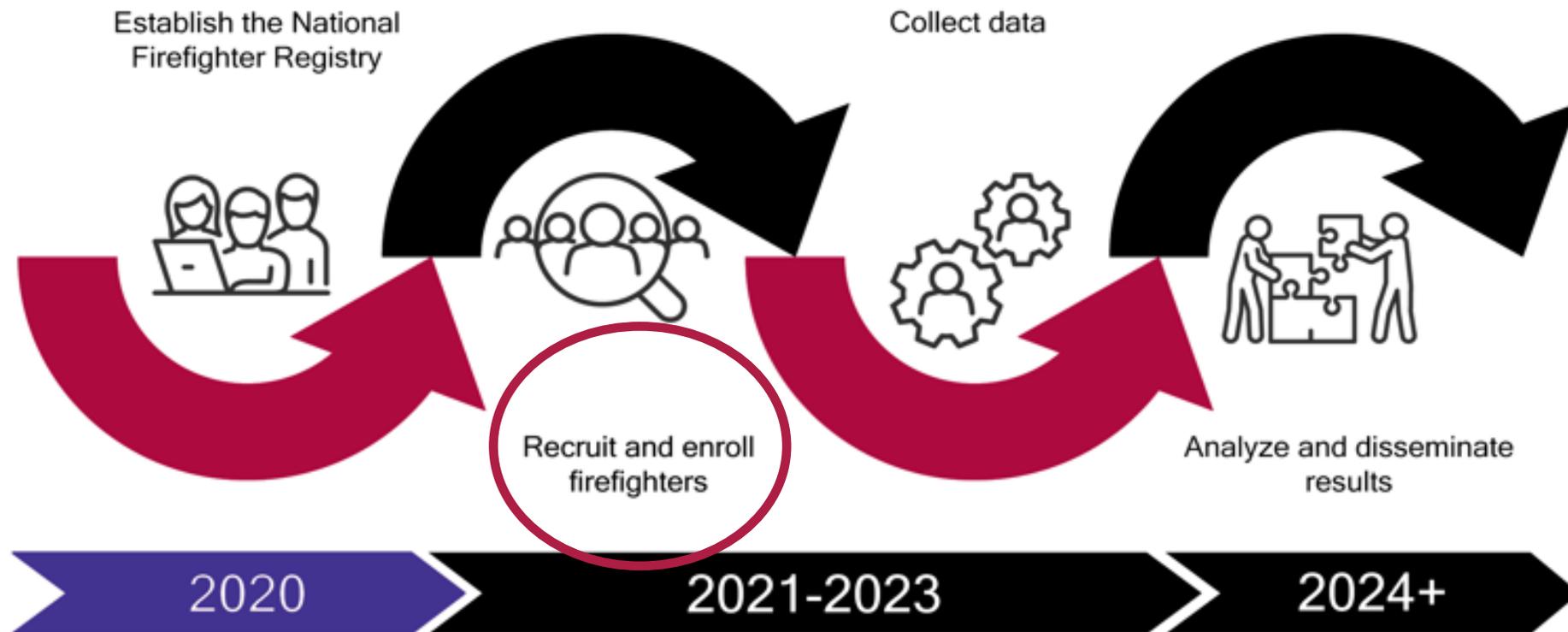


Potential Limitations

- **Generalizability may be impacted by:**
 - 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 bias
 - 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
- 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



NFR Web Portal Project Planning & Timing



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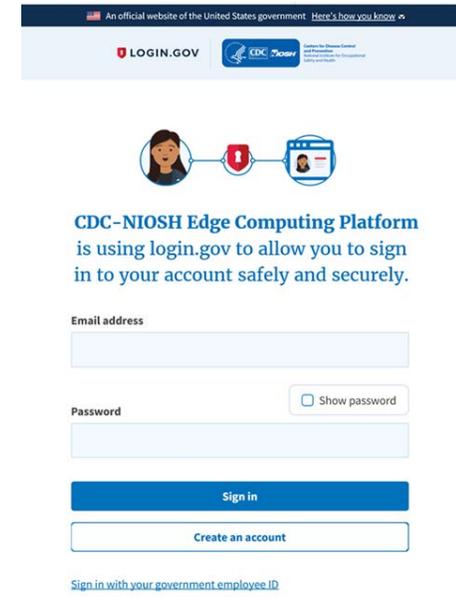
NFR PLANNING SERVICES

- Business Needs Analysis 6/2021
- Requirements Engineering 9/2021
- Solution Engineering 2/2022
- Implementation 7/2022

Estimated timeline

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Pros and Cons

Option 1

- **Pros**

- Allows participants to retrieve previously submitted user profile data for convenience in providing information longitudinally
- Captures employment information and cancer status in user profile

- **Cons**

- Requires identity proofing, which could be burdensome and intrusive
- Identity proofing would require a cell phone or second device to take and upload photographs
- Could dramatically affect participation and result in selection bias

Option 2

- **Pros**

- Does not require identity proofing
- Easier, less time consuming for participants
- Full enrollment process can be completed on any single device (no scanner or phone necessary)

- **Cons**

- Participant retrieval of data from user profile is limited to less sensitive data only
- Unclear what items are considered sensitive in nature- for example, current department
- Potentially would fail to capture all changes in department or employment status over time
- Potential for discrepancies between previously-entered information and follow-up information that would need to be reconciled

Contact

www.cdc.gov/NFR

<https://www.cdc.gov/niosh/bsc/nfrs>

NFRRegistry@cdc.gov

kfent@cdc.gov | msiegel@cdc.gov

For more information, contact CDC
1-800-CDC-INFO (232-4636)
TTY: 1-888-232-6348 www.cdc.gov

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.

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